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in Sex, Health and Society

HIV Futures Seven

The Health and Wellbeing of HIV Positive People in Australia

Jeffrey Grierson
Marian Pitts
Rachel Koelmeyer

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AFAO

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national association of people with HIV australia

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Contents

Acknowledgments

1058 people living with HIV/AIDS completed the HIV Futures 7 Survey. We are grateful for their interest in research conducted by the Australian Research Centre in Sex, Health and Society, and thank them for their willingness to participate.

We would like to express our appreciation for the input and advice provided by the three partner organisations and their membership:

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- The Australian Federation of AIDS Organisations (AFAO) and
- The Australasian Society for HIV Medicine (ASHM).

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We thank the Department of Health and Ageing (DoHA) who provide funding for this research.

This project follows on from the HIV Futures 1, 2, 3, 4 5 and 6 Studies conducted in 1997 1999, 2001, 2003, 2005 and 2008. We would like to acknowledge the researchers who contributed to these projects.

Executive summary

DEMOGRAPHICS

The HIV Futures 7 survey was completed by 1058 HIV positive Australians from all states and territories. This represents approximately 4.3% of the estimated HIV positive population.

- 92.2% were male (975), 6.7% were female (70) and 0.3% were transgender (3).
- 83.1% were gay men, 6.1% heterosexual women, 4.3% heterosexual men, 3.8% bisexual men, 0.1% lesbian women and 0.5% bisexual women. The remaining 2.1% fell into other categories.
- The respondents' ages ranged 19 to 84 years with a mean of 49.0 years and a median of 49 years. The majority of participants were Australian born (78.2%).
- Twenty two respondents (2.1%) were of Aboriginal/Torres Strait Island origin.

HEALTH

HIV antibody testing

- 24.5% tested for HIV because they became ill
- 18.9% tested as part of routine health screening
- 8.7% tested because they were a member of a risk group
- 10.9% tested because of a particular risk episode
- 2.8% were tested without their knowledge.

Current Health Status

- 71.4% rated their health as good or excellent and 62.7% rated their general well-being as good or excellent.
- Almost all PLHIV had taken a CD4/T-cell test and a viral load test.

HIV-related and other health conditions

- 22.3% of respondents had been diagnosed with an AIDS defining illness, 3.3% in the previous two years.
- 40.6% of respondents indicated that they had experienced HIV-related illnesses.
- 46.0% indicated that they had a major heath condition other than HIV/AIDS. The most common conditions were asthma (8.3%), cancer (6.4%), cardiovascular disease (e.g. high blood pressure) (7.3%), type II diabetes (4.2%), hepatitis C (6.0%).

When asked if they had experienced any of the following conditions in the previous 12 months:

- 80.2% reported low energy or fatigue
- 66.8% experienced a sleep disorder
- 41.9% experienced confusion or memory loss
- 66.8 % experienced low libido
- 23.9% reported experiencing lipodystrophy/ lipoatrohy

73.9% of respondents reported that they had undergone sexual health screening in the twelve months prior to survey.

17.5% said they had been diagnosed with an STI in the previous twelve months.

Mental health

- 34.8% of respondents had taken prescribed medication for depression in the last six months
- 48.1% had ever had a diagnosis of a mental health condition.
- 41.5% of all respondents had ever been diagnosed with depression, 17.2% in the previous two years.

Viral Hepatitis

- 18.0% had at some point had hepatitis A
- 60.6% had been vaccinated against hepatitis A
- 18.9% had at some point been diagnosed with hepatitis B, of whom:
  - 71.0% had cleared the infection
  - 13.4% had ongoing infection and
  - 5.2% had a chronic infection
- 68.9% had been vaccinated against hepatitis B
- 15.7% of respondents said they had never had hepatitis C.

TREATMENTS

Antiretroviral therapy

Antiretroviral use:

- 87.3% were currently using ARV
- 91.0% had used ARV at some time
- 80.6% of those on ARV were using a pre-formulated combination

Difficulties of taking ARV

- 37.6% of those participants currently taking ARV reported that they experienced difficulties taking them of which the major problems were:
  - 21.3% side effects
  - 21.3% remembering to take the drugs on time
  - 13.8% transporting medication
  - 9.9% taking medication in public
  - 11.3% organising meals around the drugs
  - 8.1% taking large numbers of tablets.

Attitudes to antiretroviral therapy

Does ARV mean better prospects for PLHIV?

- 86.3% of respondents believed that combination antiretroviral drugs mean better prospects for PLHIV
- 8.1% believed that it is still too soon to tell
- 24.9% believed that combination antiretroviral drugs are harmful
- 29.2% believed that the side effects outweigh the benefits of antiretroviral drugs.

Treatment breaks

- 27.9% of those currently on ARV had taken a break from ARV
- Doctors were less likely to be consulted before a break than during or afterward
- 58.3% discussed this with their doctor before the treatment break.

Dosing and adherence

- 48.9% of the sample were taking ARV twice daily
- 2.2% were taking ARV three times a day
- 47.1% were taking ARV once a day
- 49.9% said they were taking medication as prescribed 100 percent of the time, 79.8% said at least 90 percent and 86.9% said at least 80 percent. Only 7.4% said less than 50 percent of the time.

Complementary therapies

- 62.5% used vitamin and mineral supplements
- 18.2% used herbal therapies
- 16.5% used marijuana for medicinal purposes
- Complementary therapies tended to be used in conjunction with allopathic treatment.

SERVICES

Health Services

- For HIV specific treatment 51.5% saw an HIV GP/S100 prescriber and 26.8% saw an HIV specialist/physician
- For general health care treatment, 47.3% of PLHIV saw an HIV GP/S100 prescriber and 32.1% saw a non-HIV GP
- For 47.8% of respondents, these were different doctors.

Other services

Services used at AIDS organisations:

- 20.0% treatment advice
- 27.1% social contact
- 22.3% counselling
- 18.6% peer support
- 8.3% advice on legal matters.

Information

Most important source of information on treatments/HIV management:

- 77.0% said HIV GPs/S100 prescribers or HIV specialists
- 7.6% said the internet
- 5.7% HIV/AIDS organisations
- 5.7% HIV magazines and newspapers
- 0.6% social sources- friends, family etc.

Important sources of information on living with HIV:

- 32.2% said HIV GPs/S100 prescribers or HIV specialists
- 20.7% HIV/AIDS organisations
- 14.3% HIV magazines and newspapers
- 13.0% said the internet
- 12.5% social sources- friends, family etc.

Involvement with HIV/AIDS organisations

65.0% had some contact with HIV/AIDS organisations, mostly receiving newsletters or being clients of these organisations. 7.9% were employees of HIV/AIDS organisations.

THE SOCIAL WORLD OF PLHIV

Contact with other PLHIV

- 92.0% knew another PLHIV
- 15.0% had a spouse/partner with HIV
- 49.5% had acquaintances with HIV
- 70.9% spent at least some time with other PLHIV
- 12.4% spent a lot of time with other PLHIV
- 29.1% spent no time with other PLHIV
- 15.5% had been involved with the care of someone with HIV/AIDS in the last two years.

For 48.9% of respondents HIV was an important part of their identity, while for 17.5% it was an essential part. HIV status tended to be less important than identities based on sexuality, gender or family.

Disclosure

Almost all respondents had disclosed their HIV status to at least one person, generally partners, close friends and family.

For 52.8% of respondents, their HIV status had been disclosed to another person when they did not want it to be (25.4% in the last two years).

Social support

Sources of 'a lot' of social support:

- 77.8% partners/spouse
- 63.0% pets
- 43.9% doctors
- 43.6% close friends

Planning for the future

19.7% planned only one day at a time, while 53.3% planned at least one year ahead.

Relationships and sex

- Over one quarter (28.8%) of PLHIV were not having sex at present. 41.7 % of PLHIV were in a regular relationship, and a slightly smaller number had sex within the relationship (38.6%). Just under half of this group also had sex with casual partners (15.4%). 32.7% of respondents had causal partners only.
- Of those in a regular relationship 40.6% had a partner who is also HIV positive, 57.7% had an HIV negative regular partner and 1.6% a partner of unknown status. Nearly all (97.5 %) PLHIV had disclosed their status to their regular partner.
- 31.5% of the respondents had anal or vaginal intercourse with a regular partner in the past six months. Condom use with regular partners was strongly related to the HIV-status of the partner.
- 48.2% of the sample had sex with casual partners in the past six months. 25.9% of male respondents reported always using condoms with casual male partners.

Information about the most recent episode of sex with a casual partner in the previous six months was provided by over half the sample. Vaginal or anal intercourse took place in 77.2% of these instances.

Condom use with the most recent casual partner:

- 9.7% of those who had sex with an HIV+ partner
- 71.2% of those who did not know their partner's HIV status
- 60.8% of those who had sex with an HIV negative partner.

53.7% of PLHIV would prefer to be in a relationship with someone who is also HIV positive. 60.0% of PLHIV expressed some fear of rejection from potential partners if they tell of their HIV status. The majority of PLHIV (54.2%) felt HIV had a negative effect on their sexual pleasure.

Only 22.8% of PLHIV agreed with the statement *I feel more confident about unprotected sex because of the new treatments.*

One quarter of PLHIV agreed that undetectable viral load means HIV is unlikely to be transmitted (28.1%).

Legal issues around disclosure

- 45.2% agreed with the statement *I am worried about disclosing my HIV status to sexual partners because of the current legal situation*.
- 30.1% expressed some concern about the legal implications of disclosure of sexual practices to service providers.

Recreational drug use

Alcohol was the drug most commonly used by PLHIV (79.5%), and 30.2% had used tobacco in the previous 12 months.

HOME, WORK AND MONEY

Accommodation

- 34.1% were in private rental accommodation
- 41.5% owned or were purchasing house or flat
- 12.8% were in public rental accommodation (government owned)
- 3.8% were in community housing/housing co-operative
- 41.2% of PLHIV lived by themselves
- 49.2% of PLHIV lived with pets
- 76.1% of respondents had access to a car.

Employment

Just over half of respondents were currently in paid employment (58.2%), the majority of these being in full-time work (38.5% of total sample). The majority of the remainder described themselves as either not working or retired.

Most respondents said they had either left their career or in some way reduced their career goals as a result of their HIV diagnosis.

Around half of respondents who were working said that HIV has had an impact on their capacity to perform their work duties. Most commonly respondents reported that they tired more quickly, that they had difficulty concentrating and that they have had to reduce their work hours.

54.6% of PLHIV currently in work had not disclosed their HIV status to anyone at their workplace, while 16.1% did not try to keep their HIV status confidential. The most common difficulties for those who do want to maintain confidentiality at work were gossip and explaining absences from work.

Finances

47.1% of respondents identified their main source of income as a government benefit or pension. As well, more than one half of PLHIV reported experiencing at least some difficulty with meeting the cost of daily living.

Difficulty with meeting the cost of daily living:

- 60.4% difficulty paying for utilities
- 59.8% difficulty paying for clothing
- 59.3% difficulty paying for housing
- 52.3% difficulty paying for transport
- 52.1% difficulty paying for food.

26.6% of those on a government benefit had been assessed by a Commonwealth Medical Officer in the past 2 years. While this resulted in termination of benefits or change in conditions for few respondents, it caused distress for 58.9% of those assessed.

Poverty

28.6% of PLHIV are living below the poverty line. Just under one quarter of respondents have a partner with whom they share financial resources and this protects some from extreme economic hardship. Very few respondents who are earning an income from paid employment reported incomes below the poverty line whereas around half of those on government benefits are living in poverty.

Discrimination

- 7.4% experienced less favourable treatment in relation to accommodation, 2.8% in the last two years
- 27.6% experienced less favourable treatment because of HIV in relation to health services, 13.0% in the last two years
- 23.4 % experienced less favourable treatment in relation to insurance.

Demographics

This section provides an overview of the sample characteristics. The data in this section are not weighted. For a full description of the project methodology and data weighting algorithms please refer to the Appendix.

Sample demographics

The HIV Futures 7 survey was completed by 1058 HIV positive people. Given current estimates of HIV infection in Australia (Kirby Institute, 2012) this represents approximately 4.3% of the HIV positive population. Of the total respondents, 36.5% completed a paper copy of the survey, while 63.5% completed the survey on-line.

Of the survey respondents, 92.9% were male (975), 6.7% were female (70) and 0.3% were transgender (3). This sample consisted of 83.1% gay men, 6.1% heterosexual women, 4.3% heterosexual men, 3.8% bisexual men, 0.1% lesbian women and 0.5% bisexual women. The remaining 2.1% fell into other categories.

Respondents ranged in age from 19 to 84 years with a mean of 49.0 years and a median of 49 years.

The majority of participants were Australian born (78.2%), were Australian residents (98.1%) and 96.7% of the participants spoke English at home, with Asian and European languages accounting for most of the remainder.

Twenty two respondents (2.1%) indicated they were of Indigenous (Aboriginal/Torres Strait Island) origin. This compares to the Australian census estimate for 2008 of 2.5% Indigenous status in the Australian population (Australian Bureau of Statistics, 2012). Respondents came from all Australian states and territories, with the majority coming from NSW, Victoria and Queensland (see Table 1)

Table 1 – State or Territory of respondents' residence

State/territory	Frequency	Percentage of Sample
NSW	419	40.5
VIC	302	29.2
QLD	138	13.3
WA	71	6.9
SA	54	5.2
ACT	34	3.3
TAS	8	0.8
NT	8	0.8

The majority (59.4%) of respondents were from urban areas of capital cities, while 14.9% lived in outer suburban areas, 16.0% lived in larger regional centres and 9.7% lived in rural areas.

69.3% of participants were living in the same state or territory in which they were infected with HIV, while 30.7% reported living in a different state or territory.

Table 2 below shows the years in which respondents tested HIV positive and in which they believe they were infected with HIV. Overall these patterns match those of the Australian epidemic. There are 98 respondents in the sample who had tested positive in the previous two years (2010-2011/12) and 52 respondents who believe they were infected in the previous year (2011/12).

Table 2 – Years of respondent's testing positive and presumed infection (%)

Year	Tested HIV Positive	Presumed Infected
Pre 1985	5.4	12.4
1985-1989	17.8	16.3
1990-1994	15.0	14.6
1995-1999	13.0	12.1
2000-2004	16.6	18.1
2005+	32.2	26.6

517 respondents (48.9%) indicated that they were atheist/agnostic, 34.4% indicated mainstream religious identification and the remainder indicated that they either had 'other' (9.9%) or New Age spiritual beliefs (5.5%). Of those with religious beliefs, 10.3% indicated that religious beliefs were not important to them, while 40.4% indicated that these were of little importance, 33.9% that they were very important and 15.4% that they were extremely important.

The educational level of respondents to the survey was somewhat higher than the general population, as is usual in research requiring a moderate level of literacy and engagement with the research process. The educational levels are shown in Table 3 below.

Table 3 – Educational level of respondents

Level	Frequency	Percent of sample
Postgraduate University degree	226	21.6
Undergraduate University degree	200	19.1
Tertiary diploma/ Trade Certificate/TAFE	285	27.2
Leaving certificate/HSC/Year 12	137	13.1
4th form/year 10	125	11.9
Up to 3 years high school	63	6.0
Primary school only	11	1.1

Weighting

The remaining findings in this report are for weighted data. In order to ensure that the results reported in this document accurately represent the Australian population of PLHIV, comparisons were made to the Australian HIV Surveillance Report (Kirby Institute 2012) and the data were weighted to conform to the demographic profile of the Surveillance Report.

A weighting algorithm based on mode of infection, gender, state of residence and diagnosis of AIDS defining illness has been applied to all the analyses that follow. Consequently, findings are presented in terms of sample percentages rather than frequencies. Sample sizes (Ns) are given when the table represents a subset of the total sample. These Ns are weighted.

Health

This section of the report deals primarily with the physical health and experience of health of Australian PLHIV. The chapter includes a discussion of the experiences of testing positive for HIV, the current health status of participants measured both by clinical markers and self-reported health and well being, the health burden in terms of concomitant health conditions and health maintenance strategies.

HIV ANTIBODY TESTING

The experience and meanings of testing positive for HIV have changed over the history of the HIV/AIDS epidemic. In the early years of HIV in Australia, testing did not offer any particularly great advantage in treatment options and often led to increased anxiety, stigma and discrimination. With the advent of more effective treatments, the advantages of early testing have become clearer, not only in terms of medication, but also in health monitoring and social support. Testing rates remain high among community attached gay and homosexually active men in Australia (over 80%), although testing is down in Perth and Canberra (NCHSR, 2008).

Since November 2005 HIV antibody testing has been available on the Medicare Benefits Schedule and is available free of charge and pre- and post-test discussion are integral to the testing procedure (Department of Health and Ageing, 2006).

We asked respondents about a number of circumstances surrounding the time that they tested positive for HIV antibodies.

As can be seen from Table 4, 24.5% of the respondents had taken the test as a result of illness, 10.9% as a result of a particular risk episode and 8.7% because they were a member of a risk group. It is interesting to note that 18.9% gave the reason for testing as routine health screening.

Table 4 – Reasons for testing

Reason	Frequency	Percent
Became ill/ ongoing illness	255	24.5
Routine health screening	196	18.9
Particular risk episode	113	10.9
Doctor's suggestion	111	10.7
Partner tested positive	93	8.9
Member of risk group	90	8.7
Other	80	7.7
Tested without knowledge	29	2.8
Starting new relationship	26	2.5
As part of other test/research	20	1.9
Contact tracer/other health worker's suggestion	8	0.7
Required to (e.g. for migration)	5	0.5
Availability of new treatments	4	0.4
Antenatal	4	0.4
Insurance	4	0.4

Pre- and post-test counselling/discussion

Participants were asked if they had received counselling or had had a detailed discussion with their practitioner prior to being tested for HIV. Australia's current HIV testing policy (Department of Health and Ageing, 2006) recommends that health care providers engage the patient in a discussion that, apart from obtaining the individual's informed consent, also assures them of the confidentiality of the test, provides accurate information in a culturally and gender appropriate way, and assesses the patient's readiness for an HIV test.

As there has been considerable variability in pre- and post-test guidelines and practices over the years, we have only asked about the experiences of these for people diagnosed in the two years prior to survey.

22.0% of respondents who had tested positive in the previous two years indicated that they had received pre-test counselling or engaged in an HIV test discussion. Regardless of whether they received formal pre-test counselling or engaged in a discussion, most (72.0%) were satisfied with the level of support and information they had before testing. Among those unsatisfied with information or support many discussed testing that occurred as "routine" associated with other medical procedures, or testing carried out in settings that had no experience of HIV.

The national HIV testing policy guidelines (Department of Health and Ageing, 2006) recommends that a post-test discussion be provided for all individuals who have had an HIV antibody test, even if the result is negative. The guidelines recommend that a post-test discussion following a negative result reinforce HIV education messages about safe behaviours. Positive test results must be given face-to-face and the discussion which is aimed at managing the impact of a positive diagnosis on the individual, should help to identify the patient's options for support and to provide them with a referral to a suitable support agency.

69.9% of respondents who had tested positive in the previous two years indicated that they had received post-test counselling. Most (76.1%) were satisfied with the information and support they received after testing positive. Reasons for dissatisfaction were consistent with those around pre-test experiences.

CURRENT HEALTH STATUS

Experience of health and general well being

We asked respondents how they would best describe their current state of physical health and overall sense of well- being on a four point scale. The results are shown in Table 5 and Table 6 below. Close to half of the sample (45.1%) rated their physical health as good and 26.3% as excellent. This is less than the Australian population norm reported in the 2007-08 National Health Survey (Australian Bureau of Statistics, 2009) where 84.9% of the population rated their health as good, very good or excellent[1].

Almost one-third of respondents to HIV Futures 7 rated their health as fair or poor (28.6%).

1 It should be noted that the National Health Survey uses a five point scale: poor, fair, good, very good, excellent. The figure quoted above is for Australians aged 18-64, whereas the HIV Futures 7 sample was aged 18-84.

Table 5 – Respondents' self ratings of general health status

Health status	Frequency	Percent
Poor	72	6.9
Fair	225	21.7
Good	467	45.1
Excellent	272	26.3

The ratings for wellbeing were of a similar pattern to those for health. Two thirds (62.7%) rated their wellbeing as either good or excellent, while 27.3% rated this as fair and 10.0% as poor.

Table 6 – Respondents' self ratings of general well-being

Well-being	Frequency	Percent
Poor	103	10.0
Fair	282	27.3
Good	435	42.0
Excellent	214	20.7

CD4 and viral load

As with previous surveys, almost all PLHIV had taken a CD4 T-cell test (98.3%) and a viral load test (97.8%) in the previous year.

Results for PLHIV's most recent CD4/T-cell test ranged from 10 to 2600 cells/µl with a mean of 634 cells/µl and a median of 600 cells/µl.

Results for PLHIV's most recent viral load test ranged from below detectable levels to 5,000,000 copies/ml with a mean of 2,772 copies/ml and a median of below detectable level.

Table 7 shows the combined CD4 and viral load results of the sample. The results are grouped by three levels of CD4 count: little damage, moderate damage and severe damage, and four levels of viral load below detectable levels, low, moderate and high.

As different assays would have been used to assess the respondents' viral loads we have defined below detectable levels as being those responses that were less than 500 copies/ml and those where the respondent wrote in zero or below detectable level.

Table 7 – Results of most recent serological tests (percentage of total sample)

	HIV VIRAL LOAD				
CD4/Tcell count	<500	500-9999	10000 -49999	50000+	Total
500+	55.1	1.7	1.7	1.0	59.5
350-499	20.9	1.3	0.9	0.3	23.4
0-349	16.0	0.2	0.3	0.6	17.1
Total	92.0	3.2	2.9	1.9	100.0

HEALTH CONDITIONS IN ADDITION TO HIV

While there is often uncertainty about whether a particular illness may be related to HIV, treatments or other factors, we offered participants the opportunity to record these conditions within the categories of AIDS defining illnesses (ADI), HIV-related illnesses, major health conditions other than HIV/AIDS and mental health conditions. We asked respondents to indicate whether they had experienced conditions in these categories and to specify the condition and the year in which it was diagnosed.

Some recoding was undertaken, for example for a condition that did not meet the criteria for ADI, the data were transferred to either HIV related conditions or other health conditions. Regardless of the uncertainty about the aetiology of these conditions among PLHIV (and indeed physicians) we can see that there is a considerable burden of illness that goes beyond HIV infection for a significant proportion of the survey respondents.

Participants were also asked to select from a list of 10 HIV-related illnesses those that they had experienced in the 12 months prior to survey. This section will also cover co-infection with hepatitides, attitudes towards body changes and health maintenance activities.

AIDS definingillnesses

The Australasian Society for HIV Medicine (Australasian Society for HIV Medicine, 2004) lists 26 AIDS-defining conditions in their HIV management manual. These include opportunistic infections, as well as neurological and malignancy disorders. AIDS-defining illnesses are notifiable conditions in all states and territories in Australia, and a confirmation of a case requires both laboratory and clinical evidence (Department of Health and Ageing, 2004).

The category system for defining the stages of HIV disease progression was in large part based on an understanding of the progress of the disease as degenerative with little backwards movement through the categories. There are now numerous HIV positive people who have at some time experienced an AIDS defining illness but would now be classed at a less severe stage of disease progression. We asked respondents if they have ever experienced an AIDS defining illness for 3 reasons: to match and weight the data according to surveillance data; to examine issues around the burden of illness; and to understand the current health status of participants.

Around one in five respondents (22.3%) said they had been diagnosed with an AIDS defining illness at some point with 3.3% having been diagnosed with one in the previous two years (2010 to 2011/12). The most common illnesses listed by respondents in this category were Pneumocystis Pneumonia (148 people), Kaposi's Sarcoma (40 people), and Cytomegalovirus (18 people).

HIV/AIDS related conditions

Over forty percent of respondents (40.6%) indicated that they had experienced an HIV-related illness at some point. Within this group the most common conditions mentioned were dental problems (23.6% of respondents), shingles (19.3%), and skin problems (such as rashes) (18.0%).

In a separate question, participants were asked to select from a list of 12 conditions commonly associated with HIV infection those that they had experienced in the 12 months prior to survey.

Table 8 – Health conditions experienced in the past 12 months

Health condition	Percent
Low energy/fatigue	80.2
Low libido	66.8
Sleep disorder	63.1
Diarrhoea	61.8
Strange thoughts or dreams	61.8
Confusion/memory loss	41.9
Raised cholesterol/triglycerides	37.2
Nausea or vomiting	34.7
Weight loss/underweight	28.3
Peripheral neuropathy	25.3
Lipodystrophy/lipoatrophy	23.9
Insulin resistance	3.6

Attitudes towards body image

Lipodystrophy, a side-effect of treatment, is a significant quality of life issue for people on treatment. Persson (2004) has pointed out that the paradox of ART treatments is that while it removes HIV from the inside, for some, it makes it more visible on the outside, making the treatment a marker of disease.

Positive people who experience lipoatrophy have been found to score significantly lower than HIV positive people without lipoatrophy on a quality of life measure (Rajagopalan et al., 2008). These quality of life issues can be significant and Lenert et al (Lenert et al., 2002) have found in a study of HIV positive people that most would trade years of life to avoid lipodystrophy.

While there is still some debate over the most appropriate clinical case definition for these conditions, self reported body changes remain an important component of diagnosis (Carr et al., 1999, Behrens et al., 2000). To assess the impact of these we asked participants to respond to a series of statements about their body image.

These are presented in Table 9 (at bottom of page) for both the total sample, and for those who indicated that they had experienced lipodystrophy or lipoatrophy in the past 12 months. As can be seen, approximately equal numbers of the total sample of people agreed and disagreed with the other two items, while the responses of those with lipodystrophy/lipoatrophy were more likely to be suggestive of a poorer body image.

Other sexually transmitted infections

There has been an increase in the diagnoses of sexually transmitted infections (STIs) other than HIV in Australia, and particularly syphilis among homosexually active men (National Centre in HIV Epidemiology and Clinical Research, 2008). Amongst gay men in Sydney, research has found a higher prevalence of some STIs – namely syphilis and anal gonorrhoea among HIV positive men compared to HIV negative men in Sydney (Jin et al., 2007).

A similar discrepancy was observed in rates of syphilis amongst Melbourne men where the authors estimate that HIV positive men were 4.7 times more likely to be diagnosed with syphilis than negative men (Allen et al., 2008).

We asked about sexual health screening, and 73.9% of respondents reported that they had undergone such a screening in the twelve months prior to survey. We included a question in the HIV Futures 7 survey about sexually transmitted infections that participants may have been diagnosed with.17.5% said they had been diagnosed with an STI in the previous twelve months.

Table 10 – Participants diagnosed with a sexually transmitted infection in past 12 months

Diagnosis	Frequency	Percent
Gonorrhoea	70	6.7
Chlamydia	97	9.3
Genital Herpes	19	1.8
Syphilis	51	4.8
Other	12	1.2

Table 9 – Attitudes around body image (percentages of total sample, those with and without lipodystrophy)

Body image attitude		% of total sample	% of those with lipodystrophy	% of those without lipodystrophy
Changes in my body due to HIV/AIDS have made me feel sexually unattractive	strongly agree	18.5	36.5	12.4
	agree	34.6	44.6	30.6
	disagree	35.1	17.1	41.7
	strongly disagree	11.8	1.8	15.3
I am happy with the way my body looks.	strongly agree	7.7	2.3	8.8
	agree	39.4	23.9	45.1
	disagree	38.8	46.7	36.2
	strongly disagree	14.1	27.1	9.8
Body changes due to lipodystrophy make it obvious to others that people have HIV	strongly agree	13.0	29.1	8.0
	agree	31.0	44.3	26.7
	disagree	38.3	22.2	42.1
	strongly disagree	17.7	4.4	23.1

Other health conditions

46.0% of respondents indicated that they had a major health condition other than HIV/AIDS. The most common conditions listed under this heading were asthma (8.3%), cancer (6.4%), cardiovascular disease (e.g. high blood pressure) (7.3%), type II diabetes (4.2%), hepatitis C (6.0% of the total sample).

VIRAL HEPATITIS

Hepatitis is a term that refers to inflammation of the liver. Six different types of viral hepatitis have been identified so far. Hepatitis A, B and C are more commonly known in Australia but hepatitis D, E and G have also been identified. For HIV positive people, co-infection with hepatitis may affect both their health and/or their decisions in relation to antiretroviral treatments. We asked about diagnosis of, and vaccination against, hepatitis A and B, and some more detailed questions about diagnosis and experience of hepatitis C.

Hepatitis A

Around one fifth of the participants (18.0%) had at some point had hepatitis A, and 60.6% had been vaccinated against this virus.

Hepatitis B

A total of 18.9% of respondents had at some time been diagnosed with hepatitis B. Of these, 71.0% had cleared the infection, 13.4% had an ongoing infection and 5.2% had a chronic infection. In addition to those who had experienced hepatitis B infection, 68.9% had been vaccinated against this virus.

Hepatitis C

Around one quarter (28.4%) of respondents had not been tested for hepatitis C. 80.2% of the most recent hepatitis C antibody tests were taken in the previous two years and 13.7% of participants' first hepatitis C antibody tests were taken in this period.

We asked respondents if they had ever had hepatitis C, and 15.7% (N=159) said that they had. Of these, 59 people (39.2%) said they had since received a negative PCR test.

When asked how they believe they were infected with the hepatitis C virus, 46.5% said injecting drug use, 27.6% during sex, 5.7% blood transfusion or the receipt of blood products, and 1.8% through tattooing. 6.9% of respondents did not know how they were infected.

Table 11 – Respondents' reported mode of hepatitis C infection (percentage of those with hepatitis C)

Mode of infection	Percent
Injection Drug Use (IDU)	46.5
During Sex	27.6
Don't know	6.9
Blood transfusion/ Blood products	5.7
Tattooing	1.8
Other	11.6

16 respondents reported that they had completed treatment with interferon monotherapy, while 4 were currently on this treatment and four had started but not completed monotherapy.

51 people reported that they had completed combination therapy of interferon and ribavirin. 4 were currently on combination therapy and 9 had commenced but not completed therapy.

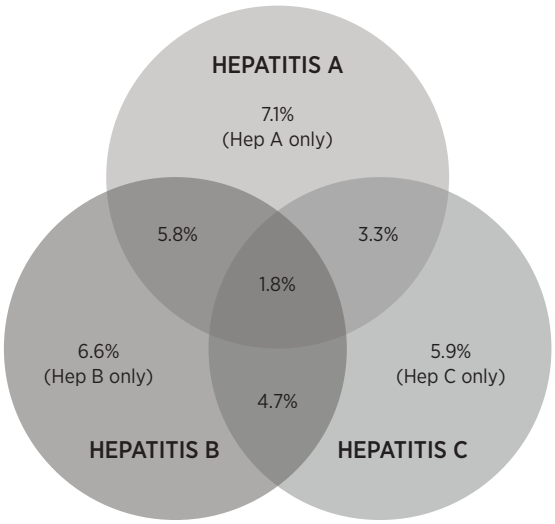
Hepatitis C co-infected participants were also asked about health monitoring and management. Around one fifth (23.8%) of co-infected PLHIV did not currently see a doctor for hepatitis C treatment or management, while 48.5% of this group saw their primary HIV doctor and 27.7% saw a separate hepatitis C doctor or specialist.

Multiple Hepatitis experience

Co-infection with a hepatitis virus has important implications for treatment of both HIV and the hepatitis. Co-infection also results in increased clinical management particularly around treatment decisions for both conditions, interpretation of clinical markers and the management of adverse consequences of treatment.

Figure 1 below shows the percentage of respondents who reported having ever had at least one of the viral hepatitides. This figure includes those with current infection and those having had it in the past, having reported clearing the hepatitis B virus or testing negative on a PCR test for hepatitis C. Of those for whom data was available on all three viruses, 19.6% had experience of one form of hepatitis infection, 13.8% of two forms and 1.8% had experienced all three.

Figure 1 – Multiple hepatitides (percentage of respondents)



MENTAL HEALTH

Mental health issues continue to figure large in discussions of the needs and status of positive people in many parts of the world. While a survey like this cannot expect to offer a clinical perspective on mental health status, we can give an overview of some of the experiences of positive people that fall within the broad area of mental well-being.

In a study of major depressive illnesses among HIV positive and negative gay men in Sydney and Adelaide, Mao et al (2009) found that gay men generally were at high risk of depression whatever their HIV status. While being HIV positive was not independently associated with an increased risk of depression, positive men had higher rates of depression associated with factors such as socio-economic deprivation, isolation and withdrawal.

Psychiatric medications

In the six months prior to completing the survey, 34.8% of PLHIV said they had taken medicines prescribed for depression. This is likely to come out as considerably higher than the 5.9% of the Australian population who reported having taken antidepressants in the previous 2 weeks in the National Health Survey (Australian Bureau of Statistics, 2009).

Diagnosis of a mental health condition

We asked respondents if they had been diagnosed with a mental health condition and 48.1% reported that they had had such a diagnosis. Of those reporting a diagnosis, the vast majority had been diagnosed with depression (87.5%, 41.5% of the total sample). 17.2% of people receiving a diagnosis of depression reported having received this diagnosis in the previous 2 years.

The next most common condition was anxiety, reported by 57.7% of those with a mental health condition (27.4% of the total sample). 20.2% of those reported having received this diagnosis over the past 2 years.

HEALTH MAINTENANCE

Attitudes to health management

Participants responded to a number of statements about health management in relation to health improvement strategies, antiretroviral therapies and complementary therapies. The items on antiretroviral and complementary therapies are presented in the relevant sections of the report.

When asked about health management strategies, almost all participants agreed that exercise; healthy eating and an optimistic outlook were important or very important strategies (see Table 12). Those who indicated that they exercised and ate well were more likely to agree with the respective statements.

Table 12 – Attitudes to health management (percentage of total sample)

Attitudes to health management		% total sample
Looking after my physical fitness is an important part of managing my HIV infection	strongly agree	46.7
	agree	49.0
	disagree	3.2
	strongly disagree	1.1
Healthy eating is an important part of managing my HIV infection	strongly agree	43.0
	agree	50.3
	disagree	5.7
	strongly disagree	1.0
Keeping an optimistic frame of mind is an important part of managing HIV infection	strongly agree	13.0
	agree	31.0
	disagree	38.3
	strongly disagree	17.7
As long as I am well I prefer not to think about HIV/AIDS	strongly agree	24.4
	agree	40.1
	disagree	30.4
	strongly disagree	5.1
Life has become more meaningful since I became HIV positive	strongly agree	13.8
	agree	30.0
	disagree	37.0
	strongly disagree	19.2

Other health monitoring

We asked a series of questions about other health monitoring activities. 21.3% had had a bone density test in the last two years and 14.4% had had a test more than two years ago. 70.2% had had a fasting cholesterol test in the last two years and 7.4% had had one more than two years ago.

84.8% had had their blood pressure taken in the previous two years and 18.6% had elevated blood pressure. The long term effects of living with HIV and medication have made health concerns such as high cholesterol, cardiovascular difficulties and osteoporosis increasingly important for positive people.

37.1% of all respondents had had an anal pap smear, 64.6% of these in the previous year. 98.3% of female respondents had ever undergone a cervical smear (Pap) test and 93.2% said they had taken one in the previous two years. Of those who had taken a pap test in the twelve months prior to survey, most (80.8%) reported that the result was 'normal'.

COMPLEMENTARY THERAPIES

We asked participants if they had used any complementary therapies in the previous six months, including therapeutic use of marijuana, and to indicate the types of therapies used and where these products or services were obtained.

In order to gain an overall picture of the use of these modalities, the question asked participants to indicate all complementary therapies they had used, not only those used for HIV/AIDS. Over three quarters of respondents (73.2%) indicated that they had used some kind of complementary medicine or therapy in the previous six months.

Over half of the sample (62.5%) had taken vitamin or mineral supplements. Over one-third (32.8%) of respondents had used massage, while 19.9% had used meditation. Around one-fifth (16.5%) of respondents indicated that they had used marijuana for therapeutic purposes.

Table 13 – Use of complementary therapies in the past six months (percentage of total sample)

Complementary therapies	Percent
Vitamin/mineral supplements	62.5
Massage	32.8
Meditation/visualisation	19.9
Marijuana for therapeutic purposes	16.5
Herbal therapies/supplements	18.2
Acupuncture	8.5
Traditional Chinese Medicine	4.2

(Multiple responses possible)

Treatments

In this chapter, we report on the treatment experiences of PLHIV. As antiretroviral treatments are the main way that HIV is managed therapeutically, we focus on participants' experiences of these, but also include a description of the medications that participants take for other health conditions.

ANTIRETROVIRAL THERAPY

Highly active antiretroviral therapy remains the single factor that has most altered the clinical outcomes for people living with HIV.

The introduction of ARV has reshaped the HIV epidemic in developed countries, and is increasingly doing so in developing nations and resource poor settings.

In the thirteen years in which these treatments have been available, there have been improvements in the efficacy and tolerability of treatments, while new combinations of drugs have simplified the drug-taking process for PLHIV.

Nevertheless, being on antiretroviral therapy involves a highly structured protocol that requires medication to be taken at specific times. Treatment can also result in difficult to manage side-effects.

In the following section we examine some of these challenges as well as the psychological and social impacts of treatment.

Of the full sample, 91.0% had used ARV at some point, and 87.3% were currently using these treatments. A summary diagram of the uptake of antiretrovirals can be found below.

Those currently using ARV

The majority of participants are now taking one of the preformulated combinations (Atripla, Truvada, Combivir, Trizivir or Kivexa) either in conjunction with another treatment (N=486) or not (N=243). Among those on combinations of individual drugs (N=157), the most common combination was one PI and one NNRTI (21 people), followed by one PI and an NRTI1 (5 people).

Figure 2 – Use of Antiretroviral Therapy

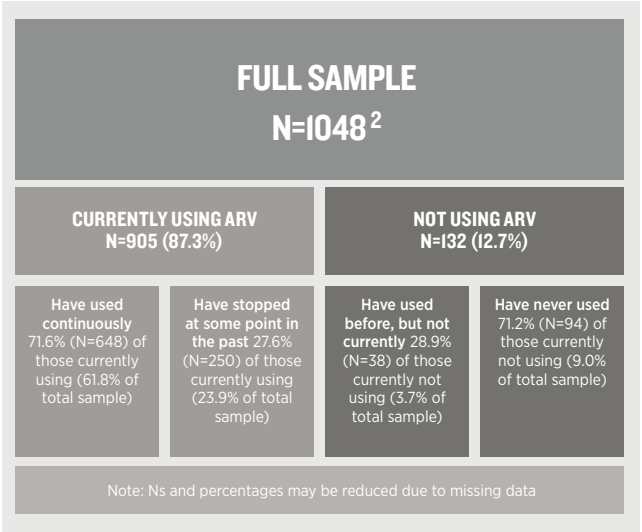


Table 14 – Antiretroviral drugs used by respondents: percentage of those currently using ARV

Nucleoside Reverse Transcriptase Inhibitors (NRTIs)	Percent
Lamivudine (3TC, Epivir)	7.7
Abacavir ,1592 (Ziagen)	3.7
Stavudine, d4T (Zerit)	0.9
Zidovudine, AZT (Retrovir)	4.8
Didanosine (ddI, Videx, Videx EC)	0.9
Zalcitabine, ddC (Hivid)	0.4
Emtriva (Emtricitabine, FTC)	0.7
Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs)	**Percent**
Nevirapine (Viramune)	0.3
Efavirenz (Sustiva, Stocrin)	6.8
Etravirine (Intelence)	5.4
Delavirdine (Rescriptor)	0.1
Nucleotide Analog Reverse Transcriptase Inhibitors	**Percent**
Tenofovir (Viread)	8.5
Protease Inhibitors	**Percent**
Ritonavir (Norvir)	25.9
Atazanavir (Reyataz)	19.7
Saquinavir (Invirase, Fortovase)	1.4
Nelfinavir (Viracept)	23.1
Indinavir (Crixivan)	0.7
Tipranavir	0.3
Telzir (fosamprenavir)	0.4
Amprenavir (Agenerase)	0.1
Kaletra (Lopinavir + Norvir,)[3]	8.2
Prezista (Darunavir, DRV)	8.0
Fusion Inhibitor	**Percent**
T-20	0.4
Combination Medications	**Percent**
Atripla (Efavirenz, Emtricitabine and Tenofovir)	20.1
Truvada (Tenofovir, Emtricitabine)	35.9
AZT & 3TC (Combivir)	3.9
AZT & 3TC & Abacavir (Trizivir)	1.3
Kivexa (abacavir and lamivudine)	20.3
Other	**Percent**
Celsentri (Maraviroc, MVC)	1.7
Isentress (Raltegravir, RAL)	19.9
Other	2.6

2 Weighted.

3 Kaletra is counted as 2 protease Inhibitors in calculation of drug combinations, but is listed here under PIs as both drugs are in the same category.

Difficulties of taking ARV

37.6% of participants who were currently on antiretroviral treatment said that they had some difficulty being on treatment. The most common problems that participants experienced were remembering to take the drugs on time (21.3%) and managing the side effects of medication (21.3%). Difficulties transporting their medication (13.8%) and taking medication in public (9.9%) were the next most common difficulties that participants reported.

Table 15 – Difficulties of taking ARV among those currently using ARV (percentage of those on ARV)

Difficulties of taking ARV	Percent
Remembering to take drugs on time	21.3
Side effects	21.3
Carrying/transporting medication	13.8
Organising meals around medication	11.3
Taking medication in public	9.9
Taking a large number of tablets	8.1
ARV drugs make it difficult to take medication for other health conditions	4.6
Medication taken for other health conditions makes it difficult to take ARV	2.2
Other	4.9

(Multiple responses possible)

Attitudes to ARV

Half of respondents were concerned about the future efficacy of their treatments: 46.5% agreed or strongly agreed with the statement *"I am worried that in the future my medication will stop working for me"*. When asked to respond to the statement *"Taking tablets gives me an unwanted reminder that I have HIV"*, 57.6% indicated agreement and 40.6% indicated disagreement.

Table 16 – Attitudes to medication: percentage of those currently using ARV

Attitudes to medication	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
I am worried that in the future my medication will stop working for me	10.0	29.8	34.2	12.3	13.6
Taking tablets gives me an unwanted reminder that I have HIV	12.4	28.2	35.7	21.9	1.7

Health status of those using ARV

As expected, those taking ARV had markedly lower viral loads. As Table 17 shows, the overwhelming majority of respondents who were on ARV had an undetectable viral load at their most recent testing.

Table 17 – Viral loads of those taking and not taking antiretroviral therapy (percentage within rows)

VIRAL LOAD ON MOST RECENT TEST

ARV use	50000+	10000 -49999	500 -9999	Below detectable levels
Current	0.5	0.8	1.1	97.6
Past	13.0	13.0	17.4	56.5
Never	20.0	32.0	32.0	16.0

$\chi^2_{(3,2)} = 469.869$, $p<0.001$

Those taking ARV and those who had never taken it were more likely to have a CD4 count over 500 than those who had previously.

Table 18 – CD4 of those taking and not taking antiretroviral therapy (percentage within rows)

CD4 ON MOST RECENT TEST

ARV use	0-349	350-499	500+
Current	20.2	22.2	57.7
Past	21.2	42.4	36.4
Never	11.4	22.7	65.9

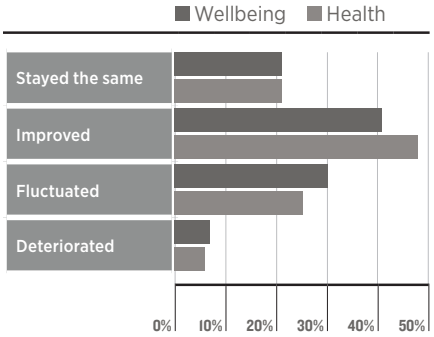
$\chi^2_{(2,2)} = 12.571$, $p=0.014$

Those who have never taken ARV were less likely to have had an AIDS defining illness (1.1% compared to 24.8% among those currently taking antiretroviral treatments and 20.5% among those currently not taking antiretrovirals).

When asked to rate the effect of commencing ARV on their physical health, 47.8% said that their health improved, 24.0% said it had fluctuated, 22.3% said it had stayed the same and 5.9% said it had deteriorated.

When asked about the impact of ARV on their overall feeling of well-being, 41.1% said it had improved, 30.1% said it had fluctuated, 22.2% said it had stayed the same and 6.6% said it had deteriorated.

Figure 3 – Effect of commencing antiretroviral medication on health and wellbeing (percentage of those taking ARV)



THOSE NOT CURRENTLY TAKING ARV

Of the 12.7% of the sample who were not using any antiretrovirals, 28.9% (N=38) had done so in the past. At the time that they stopped using ARV, most were using a combination of 3 drugs.

Reasons for stopping ARV treatment

Just as the side effects of medication was one of the main difficulties that participants on ARV experienced, this was the most common reason that those who were not currently on treatment gave for stopping ARV therapy (18.1%).

A sizable number (15.4%) also said that they had stopped treatment because their doctor had recommended it. (See Table 19).

Table 19 – Reasons for stopping ARV among those who have stopped ARV treatment

Difficulties of taking ARV	Percent
Side effects	18.1
Recommended by my doctor	15.4
Difficulty organising meals around medication	4.8
Difficulty taking medication in public	2.7
Taking part in a clinical trial	2.2
Difficulty taking a large number of tablets	2.1
Difficulty carrying/transporting medication	0.0
Other	16.8

(Multiple responses possible)

Those who have never used antiretroviral drugs

9.0% (N=94) of the respondents had never used antiretroviral treatments. Of these 86.1% said they would consider using antiretroviral drugs in the future.

ATTITUDES TO ANTIRETROVIRAL THERAPY

Antiretroviral treatments have an impact on many parts of people's lives, not just on their physical health. As in previous surveys, we asked respondents to respond to a series of statements about treatments. These fall into three broad areas: decision making around treatments, relationship with their doctor, and optimism about treatments. These findings can be seen in Table 20 below.

Treatment decision making

Most respondents indicated that they disagreed with the statement *I am healthy now and don't need to use antiretroviral drugs* (81.7%). Those who agreed with this statement were more likely to be those not currently using any antiretroviral drugs and who rated their physical health more positively.

Relationship with doctor

As with previous surveys, most respondents (88.3%) agreed with the statement *My doctor and I work together to find the best treatment for me*, with few expressing uncertainty. Most respondents (82.5%) agreed with the statement *My doctor knows more about the treatment of HIV than I do*.

Treatment optimism

Optimism about the value and effectiveness of antiretroviral treatments continues to characterise the Australian experience, but tempered as always with concerns about the impact and long term effectiveness of these treatments.

Only 4.3% of respondents agreed with the statement Combination antiretroviral drugs are ineffective. This belief in effectiveness is tempered by an awareness of the potential harm of these therapies as evidenced by the agreement with the statement that *Combination drugs are harmful* (19.1% agree, 5.8% strongly agree).

This harm may in part be that experienced as side effects. Around one in five (29.2%) respondents agreed or strongly agreed with the statement *The side effects of antiretroviral drugs outweigh the benefits*, while 9.5% were unsure.

Table 20 - Attitudes to antiretroviral drugs: percentage of total sample

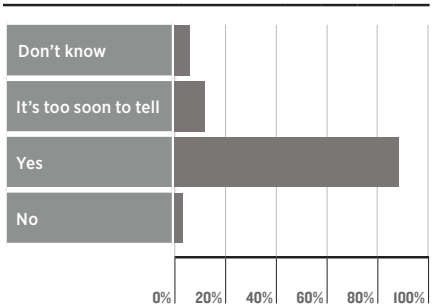
Attitudes to medication	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
I am healthy now and don't need to use combination antiretroviral drugs	51.8	29.9	7.2	6.4	4.7
Combination antiretroviral drugs are harmful	31.3	29.3	19.1	5.8	14.4
Combination antiretroviral drugs are ineffective	57.5	29.9	1.7	2.6	8.4
New treatments will be developed in time for me to gain benefits	5.9	7.1	42.3	22.7	21.8
HIV treatments will stop me dying from AIDS	5.1	13.6	31.4	32.3	17.6
My doctor knows a lot more about the treatment of HIV than I do	5.2	9.4	37.9	44.6	2.9
My doctor and I work together to find the best treatment for me	4.2	5.4	41.4	46.9	2.1
The side-effects of antiretroviral drugs outweigh the benefits	26.4	34.9	17.0	12.2	9.5
Medical treatments for HIV/AIDS make safe sex less important than it was	39.9	35.4	14.9	4.2	5.6
Undetectable viral load means HIV is unlikely to be transmitted to a sexual partner even if I have sex without a condom	29.5	34.9	23.4	4.7	7.5

There was considerable uncertainty about the long term benefit of treatment. 21.8% of respondents said they were unsure when asked to respond to the statement *New treatments will be developed in time for me to gain benefits*, with most of the remainder agreeing.

Similarly, 17.6% were uncertain when asked if *HIV treatments will stop me dying from AIDS*. Agreement with this statement was indicated by 63.7% of respondents.

In addition to these items, respondents were asked to indicate how much they agree with the statement *Antiretroviral drugs mean better prospects for most people*. Most (86.3%) agreed with the statement.

Figure 4 – Respondents' response to the statement Antiretroviral drugs mean better prospects for most people



TREATMENT BREAKS

Treatment breaks may take a number of forms and be undertaken for a range of reasons (Grierson et al., 2004b). While there is considerable discussion in the medical community about the potential benefits and dangers of treatment interruptions, our main emphasis is on the motivations, experiences and consequences of breaks for HIV positive people. To understand the experience of breaks, we asked respondents to give us some detailed information about their most recent break.

In all, 27.9% of those respondents currently using antiretroviral medication had taken a break from these at some point.

Most recent treatment break

The date of the commencement of most recent treatment break was provided by 88% of those that had ever taken a break. Of these 24.8% had taken their most recent break in the two years prior to survey and 16.7% in the previous one year.

We asked participants to describe the reasons for taking the break within two major categories: lifestyle and clinical reasons.

A discussion of the differences between those who take treatment breaks for lifestyle reasons and those who take breaks for clinical reasons can be found in our article on this topic (Grierson et al., 2004b). Just under half (52.3%) indicated that there were lifestyle reasons for taking a break.

Of those taking a break in the previous two years, 65.8% said there was a lifestyle reason. The specific reasons are given in Table 21 below. The most common reason given was travel (17.8% of those taking breaks) followed by to clean out the system (16.3%).

Table 21 – Lifestyle reasons for taking breaks (percent of those taking breaks and percentage of those taking a break in the previous 2 years)

Lifestyle reasons for taking breaks	Total taking breaks	Last two years (n=41)
Travel	17.8	13.7
Clean out my system	16.3	12.2
It didn't fit my lifestyle	7.9	11.2
Taking drugs at the right time was too difficult	9.8	12.3
The financial burden became too heavy	8.2	18.1
A special event	3.7	12.0
Other	30.0	37.9

(Multiple responses possible)

When asked if there was a clinical reason for taking the break, 38.5% of those that had taken a break indicated that there was. Of those taking a break in the previous two years, 30.8% said there was a clinical reason.). Table 22 below details the clinical reasons for breaks. The most commonly cited reason was that the side effects of treatment became too severe (17.5% of all those taking breaks), 11% indicated that the break was on the recommendation of their doctor.

Table 22 – Clinical reasons for taking breaks (percent of those taking breaks and percentage of those taking a break in the previous 2 years)

Clinical reasons for taking breaks	Total taking breaks	Last two years (n=19)
Side effects became too severe	17.5	17.5
Recommended by my doctor	11.0	4.9
Drug resistance developed	5.7	1.5
Changing regimens	2.9	1.5
Liver toxicity problems	5.4	3.3
Taking part in a clinical trial	2.6	0.0
Recommended by other health professional	0.4	1.5
Complications with Hep C	1.6	0.0
Other	12.3	17.8

(Multiple responses possible)

We also asked about the involvement of the participant's doctor in these breaks. Participants were less likely to have talked to their doctor about the break prior to taking it (58.3%) than they were during the break (57.2%) or afterwards (90.7%).

For those taking a break in the previous two years, fewer talked to their doctor about the break prior to taking it (28.2%) during the break (42.2%) and afterwards (82.0%).

We were also interested in the outcome of the treatment breaks, both in terms of clinical markers and experience of health and well-being. Around two fifths of respondents said that their health remained stable, 27% said their health worsened, while 20% reported fluctuating health and 12% improved health.

When asked about their general well-being, a similar proportion said that it had remained stable (35.8%).

Table 23 – Effect of break on health and well being (percentage of those taking break and percentage in last 2 years)

Effect of break on health and well being	Health		Well being	
	All	last 2 years	All	last 2 years
Stayed the same	40.1	49.2	35.8	42.4
Improved	12.4	12.5	24.0	19.1
Fluctuated	20.0	22.3	21.5	18.6
Got worse	27.4	16.1	18.7	19.8

The impact of these breaks on clinical markers was less positive. The majority of respondents indicated that their viral load had increased, and their CD4 count had decreased as a result of the break. These data are presented in Table 24.

Table 24 – Effect of break on viral load and CD4 (percentage of those taking break)

Change in viral load due to break	Percent
Decrease (improve)	5.4
Stay the same	20.1
Fluctuate	9.6
Increase (worsen)	64.9

Change in viral load due to break	Percent
Increase (improve)	6.3
Stay the same	21.6
Fluctuate	10.8
Decrease (worsen)	5.4

DOSING AND ADHERENCE

Adherence to the antiretroviral treatment regime is important for treatment to be effective and to prevent the development of resistance to medications. The degree of adherence required is far greater than that of other health conditions. It is estimated that for the majority of people on antiretroviral treatments, adherence of more than 95% is necessary for successful viral suppression and immune response (Chen et al., 2007).

While the consistency of adherence directly affects the health outcomes for PLHIV, many factors can have an impact on consistency. These include the complexity of the drug regime, a person's emotional well being, the management of side effects, lifestyle fit, and communication with friends and doctors (Beusterien et al., 2008).

One study has found that adherence consistency tends to decrease over time (Mannheimer et al., 2002)

Respondents were asked the number of times they took a range of medications per day. On average, PLHIV were taking medication twice a day (range 0 to 23, median=2). The number of times they were taking specific types of medication is shown in Table 25 below. 48.9% of the sample were taking ARV twice daily, 2.2% three times a day and 47.1% once a day.

Table 25 – Number of times participants take medications (for those taking class of medication)

Medications	Mean	Median	Range
Antiretroviral drugs	1.63	2.00	1-10
Complementary therapies	1.69	2.00	1-7
Medication for other health conditions	1.80	1.00	1-11

Participants who were currently using antiretroviral medication were asked over the past month, what percent of the time they were able to take their antiretroviral medications exactly as the doctor prescribed them. 49.9% said 100 percent of the time, 79.8% said at least 90 percent and 86.9% said at least 80 percent. Only 7.4% said less than 50 percent of the time.

PRESCRIPTIONS

We asked participants who prescribed their antiretrovirals. In recognition of the multiple prescribing sites people utilise, respondents were able to nominate more than one source.

Over half (53.4%) of PLHIV got their prescriptions for antiretroviral drugs from a GP who specialises in HIV/ S100 prescriber.

A smaller proportion (26.5%) obtained their prescription from a specialist in an outpatient clinic, while fewer obtained them from a doctor at a sexual health centre (22.7%), another GP (1.2%), or from a HIV specialist while an inpatient (2.9%).

Overall 69.2% were satisfied with their current prescribing arrangement, with many indicating a preference for using a local pharmacy to collect medication, rather than the more limited arrangement currently in place.

Services

This section discusses the engagement of PLHIV with a range of services. A key component of the Australian response to HIV has been the establishment of HIV specific services, both within health systems (specialist HIV wards in hospitals, high HIV caseload general practitioners and sexual health services for example) and through community and volunteer organisations. There has also been considerable energy expended on sensitising mainstream services to issues specific to HIV/AIDS and the affected communities.

HEALTH SERVICES

Treatment

We asked respondents to identify the physician they see for the clinical management of their HIV and for general health issues. HIV GPs (S100 Prescribers) were the key physicians for both HIV specific and general health management. HIV specialists were also the primary providers for a significant proportion of PLHIV. The distinction between these categories reflects the different healthcare systems in different states and territories, and the availability of these physicians in regional areas. HIV GPs were more likely to be nominated as the primary provider of both general and HIV-related treatment by those living in the inner suburbs of capital cities, than those living in the outer suburbs, regional centres or rural areas. Combined, HIV GPs and specialists were the primary physicians for 78.3% of respondents for HIV specific management and for 55.0% of respondents, for general health management.

Table 26 – Physician used for general and HIV related treatment: percentage of total sample

Physician used	For general treatment	For HIV specific
HIV GP/S 100 Prescriber	47.3	51.5
Other GP	32.1	3.4
HIV specialist	7.7	26.8
Doctor at sexual health centre	7.0	14.8
Other doctor	2.1	0.5
Other	3.7	3.0

52.2% of respondents said that the doctor they saw for general medical services was the same doctor they saw for HIV-related treatment. Of those who saw a different doctor, 97.5% said that that doctor knew their HIV status.

Services used at HIV organisations

Participants were asked whether they were currently using a range of services through an HIV/AIDS organisation. Social contact with other PLHIV was the most commonly cited use with over one quarter of respondents selecting this item. HIV/AIDS organisations were also used for counselling, treatments advice, and pharmacy services by substantial numbers of respondents.

Table 27 – Percent of respondents who use services through HIV/AIDS organisations

Service	Percent
Social contact with other PLHIV	27.1
Counselling	22.3
Treatments advice	20.0
Pharmacy services	27.1
Peer support	22.3
Financial assistance	20.0
Legal advice	27.1
Financial advice	22.3
Other	20.0

(Multiple responses possible)

INFORMATION

One of the most distinctive characteristics of the HIV/AIDS epidemic has been the degree to which those infected with the virus have become highly active health consumers.

This is reflected not only in the emergence of a strong community sector and advocacy structure, but also in the way in which individual positive people actively engage with their healthcare providers and actively seek out a diverse range of information on clinical and social aspects of the virus and the epidemic.

Clinical information and most specifically information on the efficacy and consequences of treatment in the HIV/AIDS area is not the sole province of health professionals.

In the previous HIV Futures surveys and in other research we have conducted, we have demonstrated that positive people access information on HIV treatments, management and social aspects from a range of sources including the medical literature, the community sector, health professionals and peers.

Sources

Respondents were asked to nominate from a list of potential sources, those that were important sources of information on HIV including treatments management, and living with HIV.

Table 28 – Sources of information about treatments and living with HIV (percentage of sample)

Source	Percent
HIV Doctor (specialist or HIV GP/S100 prescriber)	92.1
Publications from HIV or AIDS groups	53.8
Internet	50.7
HIV or AIDS community organisations (for example, Positive organisations, AIDS Councils etc.)	48.8
Social sources (HIV-positive friends, other friends, family etc.)	36.4
Other healthcare professional	23.4
Publications from other sources	15.8

(Multiple responses possible)

Information about HIV treatment and management

When asked in a separate question to nominate their most important sources of information about treatments and health management, 77.7% of respondents nominated their HIV doctor (GP or specialist) as the most important source, followed by the internet (7.6%).

Information about living with HIV

When asked to identify the most important sources of information about living with HIV, 32.2% nominated their HIV doctor (GP or specialist), and 20.7% said HIV or AIDS community organisations .

Table 29 – Most important sources of information about treatments and living with HIV (percentage of sample)

Most important sources	HIV Treatment and Management	Living with HIV
HIV Doctor (specialist or HIV GP/S100 prescriber)	77.0	32.2
Internet	7.6	13.0
HIV or AIDS community organisations (for example, Positive organisations, AIDS Councils etc.)	5.7	20.7
Publications from HIV or AIDS groups	5.7	14.3
Publications from other sources	1.4	1.6
Other healthcare professional	1.1	2.2
Other	1.0	3.5
Social sources (HIV-positive friends, other friends, family etc.)	0.6	12.5

Lack of information

We asked respondents whether lack of information made it difficult for them to make decisions in certain areas and over a quarter (28.7%) agreed that this was the case. When asked to identify the domains in which this applied, employment and financial planning also figured prominently, with 13.0% of respondents identifying lack of information about work/employment and 12.4% financial planning. In the clinical realm, 14.8% nominated the management of side effects, while 13.8% nominated interactions between ARVs and other drugs Information about complementary therapies was identified by 12.3%.

Table 30 – Issues where participants lack information (percent of total sample)

Issues	Percent
Managing ARV side effects	14.8
Interaction between ARV and other drugs	13.8
Work/employment	13.0
Financial planning	12.4
Legal issues	12.3
Using complementary therapies	12.3
Changing ARV	10.5
Using ARV	9.6
Taking a break from ARV	8.7
Recreational drug use	6.3
Having children	4.3

(Multiple responses possible)

INVOLVEMENT WITH AIDS ORGANISATIONS

Participants were asked about their involvement with HIV/AIDS organisations. 65.0% of the sample had some contact with HIV/AIDS organisations.

Of these, 63.8% received newsletters and mail outs, 54.1% were clients, 45.8% were members, 35.8% accessed information on websites, 14.5% were volunteers and 7.9% were employees.

Of those that volunteered, they did so for between 1 and 45 hours per week (median = 4 hours/week).

The Social World of PLHIV

This chapter examines the collective experience of HIV from a number of perspectives. While for some people HIV may be a profoundly isolating experience, within Australia the experience of HIV has been overwhelmingly a collective one.

HIV is not only experienced by individuals, but also by communities and social networks. HIV identity is managed though contact with other positive people, through the disclosure of status, both willingly and unwillingly, and through engagement with the community sector. Here we explore some of these issues through the experiences of the respondents to this survey.

CONTACT WITH OTHER PLHIV

Very few HIV positive people (8.0%) did not personally know anyone else with HIV. Gay men were significantly less likely to know no-one else with HIV than other respondents. Most positive people had an HIV positive friend (73.2%) and many had either an HIV positive partner or ex-partner (15.0% and 25.1% respectively). 15.5% of respondents had been involved in the nursing or care of another positive person at some time in the last two years.

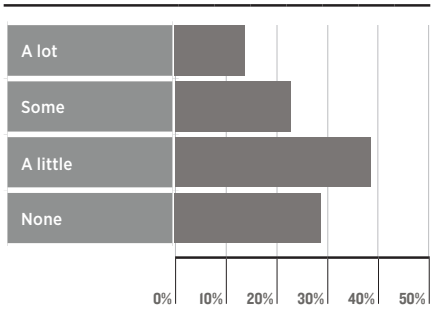
Table 31 – Other HIV positive persons known by respondent

Positive Persons	Percent
Friend	73.2
Acquaintance/Member of support group	49.5
Former partner/spouse	25.1
Partner/spouse	15.0
Other relative	3.6
Son/daughter	0.7
Online friend or buddy	30.0
Other	6.0
No-one	8.0

(Multiple responses possible)

Two thirds of the respondents spent at least some time with other positive people (70.9%). The 12.4% who indicated that they spend a lot of time with other PLHIV were more likely to be those who work or volunteer for an HIV/AIDS organisation.

Figure 5 – Time spent with other positive people



DISCLOSURE

Respondents were asked who they had disclosed their HIV status to (see Table 32). Not surprisingly, most (79.9%) had disclosed to close friends, and most (90.2%) of those in relationships had disclosed to their partner.

Within families, people were most likely to have disclosed to siblings (55.8%) although many had disclosed to parents (43.9%). Only 3.8% had not disclosed their HIV status to anyone.

Table 32 – People the respondent has disclosed their HIV status to

People the respondent has disclosed to	Percent
Close friends	79.9
Positive friends	60.9
Siblings	55.8
Partner/spouse	50.5
Parents	43.9
Other friends	28.9
Work colleagues	27.6
Son/daughter	9.4
Neighbours	15.2
People from own ethnic community	5.5
No-one	3.8
Specific sub-populations	
Partners (% of those in a regular relationship)	90.2
Work colleagues (% of those currently employed full time)	31.5
Work colleagues (% of those currently employed part time)	37.9
Son/daughter (% of those with children)	48.8

(Multiple responses possible)

Unwanted disclosure

Respondents were asked if their HIV status had ever been disclosed without their permission. 52.8% said that it had at some point, and 25.4% said that this had happened in the previous two years.

When asked if this disclosure had a negative effect, 67.5% said it had. When asked who disclosed their status, they were most likely to nominate friends. (see Table 33). In part these data reflect those that are most likely to be aware of the respondent's HIV status.

Table 33 – Sources of unwanted disclosure (percentage of those experiencing unwanted disclosure)

Sources of unwanted disclosure	Percent of those who have ever experienced unwanted disclosure (N=542)	Percent of those who have experienced unwanted disclosure in the last 2 years (N=261)
Close friends	13.4	24.7
Other friends	12.9	26.6
Work colleagues	8.9	16.0
Partner/Spouse	6.0	10.7
HIV positive friends	7.2	17.3
Other	8.9	25.2
Sibling	5.7	9.8
Workers in a healthcare setting	7.3	14.3
Parents	4.2	6.6
Neighbour	3.1	6.5
Other family member	4.4	9.6
Staff/volunteers at community organisation	4.2	8.6
Son/daughter	0.8	1.2
People from ethnic community	0.9	1.8

(Multiple responses possible)

The place of HIV in people's lives

HIV affects many parts of people's lives in both positive and negative ways. Knowledge of one's HIV status can be something that dominates some people's sense of who they are, while for others it will be a minor facet of their self-image. These different experiences of HIV status can have significant implications for the provision of services and the targeting of education for positive people.

To explore this issue, we asked *When you think of all the things that make you who you are, how important are each of the following aspects of yourself?* The categories and results are given in Table 34.

Table 34 – Importance of personal characteristics to respondents' sense of identity

Importance of personal characteristics	Essential	Important	Not important	Irrelevant
Sexuality	30.6	45.5	15.0	8.9
Family	27.6	46.6	15.7	10.1
Gender	29.8	40.8	16.4	13
HIV status	17.5	48.9	21.2	12.4
Career	16.2	44.6	19.0	20.3
Religious beliefs	7.1	20.6	26.7	45.6
Parenthood	7.9	14.3	19.1	58.7
Ethnicity	5.9	24.0	32.1	38.1
Drug use (rec/illegal)	2.8	13.1	30.1	54.0

A rating of 'essential' indicates that the characteristic is an essential component of the individual's identity.

A rating of 'important' indicates that the characteristic plays a large part in how PLHIV see themselves, but may have greater or lesser relevance depending on the context.

A rating of 'not important' indicates that the characteristic only has very context specific relevance and does not generally enter into their self-image.

A rating of 'irrelevant' indicates that the characteristic plays no part in their self-image.

While our primary focus in this area was on the importance of HIV identity, we have included other characteristics, both as points of comparison and as a way of more fully describing PLHIV.

The characteristics examined were sexuality, gender, recreational drug use, ethnicity, parenthood and career.

Almost half (48.9%) of positive people in this study considered their HIV status an important, but not essential aspect of their make-up, while 17.5% considered it to be an essential characteristic. This is in contrast to sexuality and gender, where around 30% of the sample considered each of these to be essential characteristics.

Social support

We asked participants about the amount of social support they received from a range of sources including household members, social contacts and service providers.

The ratings are shown in Table 35 below with those for whom the category was not applicable excluded from each row. Participants were most likely to have nominated their partner or spouse as providing a lot of support (77.8% of those with partners), followed by their pets (63.0% of pet owners). Around half of participants also received a lot of support from their doctors (43.9%) and close friends (43.6%).

Table 35 – Social support received from different sources: percent who gave valid responses for each category

Importance of personal characteristics	A lot	Some	A little	None
Partner/spouse	77.8	10.3	5.5	6.3
Pets	63.0	19.8	9.8	7.4
Doctor	43.9	32.4	20.0	3.6
Close friends	43.6	29.8	17.8	8.7
Parents	31.7	24.3	16.9	27.0
Children	32.6	16.7	14.4	36.3
HIV positive friends	28.1	32.6	28.4	10.9
Family	25.2	22.2	27.6	25.0
Siblings	24.1	22.5	24.5	28.8
Health care workers	23.4	30.9	23.6	22.1
Counsellor	26.3	25.0	22.6	26.1
Volunteer carer	18.4	9.9	12.4	59.3
Religious or spiritual advisor	18.5	18.2	15.4	47.9
Online Buddy	13.2	27.5	35.6	23.8
PLHIV groups	13.1	22.1	33.3	31.5

When we examine the sources that people rated as providing no support, the highest ranking category was volunteer carer, where 59.3% of those with a carer said they received no support from them. Religious or spiritual advisors were also considered a source of no support for 47.9% of those with such a source.

Participants were more likely to have rated a source as supportive if they had disclosed to them for all categories (except pets).

Attitudes to HIV status

Two additional items were included that examine individual's relationship to their HIV serostatus. Participants were asked whether they agreed with the statement *As long as I am well I prefer not to think about HIV/AIDS.* Over half the respondents agreed or strongly agreed with this statement. The second statement participants were asked to respond to was *Life has become more meaningful since I became HIV positive.* 43.8% agreed or strongly agreed with this statement. See Table 36 below

Table 36 – Attitudes to HIV status

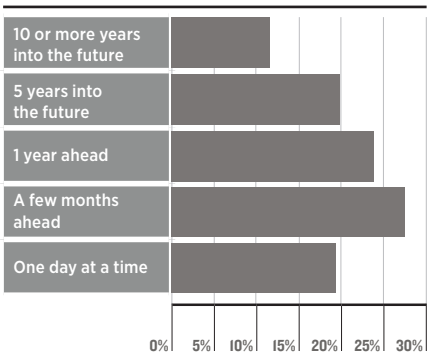
Attitudes to HIV status	Strongly agree	Agree	Disagree	Strongly disagree
As long as I am well I prefer not to think about HIV/AIDS	24.4	40.1	30.4	5.1
Life has become more meaningful since I became HIV positive	13.8	30.0	37.0	19.2

Planning for the Future

A core concern of the HIV Futures surveys is how people with HIV view their future, particularly how far into their future they plan. One fifth (19.7%) planned their life one day at a time and 27.0% planned only a few months ahead. Over half of the respondents planned for at least a year with 20.0% planning one year ahead, 21.9% planning five years ahead and 11.4% planning ten years or more ahead.

This profile of the population has changed very little since the first HIV Futures survey. Those with longer time frames tend to be those who have been HIV positive for a shorter period, have lower viral load, higher CD4 counts, and have not had an AIDS defining illness.

Figure 6 – Time frame for future planning



RELATIONSHIPS AND SEX

In this section we discuss a range of issues to do with the sexual lives and intimate relationships of PLHIV. While there is some attention paid to sexual practice, our intention is not to characterise PLHIV as a group posing a risk of HIV infection to HIV negative people. To this end, we have taken care to characterise the HIV risk reduction strategies employed by HIV positive people in sexual relations.

We have also attempted to address other aspects of sex and relationships that are all too often absent from the literature in this area. This includes issues of sexual pleasure, the establishment of relationships and the consequences of community stigma for both sexual lives and other intimate relationships.

Relationships

Respondents were asked about current sexual relationships. The results are presented in Table 37 below. Over one quarter of the sample said that they had no sex at present.

A similar though smaller proportion reported that they had a regular relationship only, while slightly more said that they had casual sex only, and slightly fewer that they had a regular relationship plus casual sex. When this item is broken down by sex and sexuality, we find significantly different patterns between three groups of PLHIV. Heterosexual men were more likely than other PLHIV to report that they had no sex at present.

Table 37 – Type of sexual relationship(s) by gender and sexuality of respondent (percentage)

Attitudes to HIV status	Gay or Bisexual men	Hetero -sexual men	Women	Total
I have no sex at present	26.8	49.9	38.1	28.8
I have casual sex only	36.6	6.7	6.7	32.7
I have a regular relationship with one person, and I have sex with other people	17.5	0.0	4.8	15.4
I have a regular relationship with one person, and I do not have sex with other people	16.1	43.4	48.8	20.0
I have a regular relationship with two or more people	3.1	0.0	1.6	3.1

Women were more likely to report that they had one regular sexual partner and no casual sex. Gay and bisexual men are more likely to report that they had a regular sexual partner and also had casual sex.

When asked if they were currently in a regular relationship, around two fifths (41.7%) said they were. This is slightly higher than the proportion of the sample that report having sex with a regular partner in Table 37 above (38.6%), as some in a regular relationship did not have sex.

Regular partners

Of those in a relationship with a regular partner, 40.6 % reported that their partner was also HIV positive (generally described as a sero-concordant relationship). The remainder were in serononconcordant relationships. This remaining group is made up of 57.7% of those in relationships that report that their partner is HIV negative (a serodiscordant relationship) and 1.6% who report that they don't know their partner's HIV status. Nearly all PLHIV (97.5 %) had told their regular partner that they were HIV positive.

We have reported the data in the following tables on sexual practice and condom use in numbers rather than percentages, as the small sub-samples would give an inflated view of the proportions in some categories. PLHIV in regular relationships were asked about the sex they had with their regular partner. Overall, 28.3% of the total sample had anal or vaginal sex with a regular male partner in the six months prior to completing the survey and 3.2% had anal or vaginal sex with a regular female partner in the previous six months. Condom use with regular partners can be seen in Table 38 below.

Table 38 – Condom use in penetrative sex with regular partner by respondent and partner gender

Number of these that used condom (N=322)	Never	Sometimes	Usually	Always
Female respondents N=49				
With regular male partner	17	6	3	15
Male respondents N=273				
With regular male partner	132	39	19	64
With regular female partner	10	6	3	9

If we look at these data in terms of relationship sero-concordance, considerable clarity is given to the patterns of condom use.Unprotected vaginal or anal intercourse is more likely to have occurred in sero-concordant relationships than in sero-nonconcordant relationships.

Table 39 – Condom use with regular partner by respondents' gender, partners' gender, and partners' sero-status

Number of these that used condom	Never	Sometimes	Usually	Always
SERO-CONCORDANT Relationships				
Female respondents				
With regular male partner	7	2	3	0
Male respondents				
With regular male partner	85	7	2	2
With regular female partner	5	0	1	1
SERO-NONCONCORDANT Relationships				
Female respondents				
With regular male partner	4	4	3	9
Male respondents				
With regular male partner	30	23	13	49
With regular female partner	3	4	8	17

Casual partners

Almost half (48.2%) of the sample reported that in the six months prior to completing the survey they had had sex with one or more casual partners. When asked the HIV status of their casual partners, 11.8% reported that all of their casual partners were HIV positive, 51.1% reported that some of their casual partners were HIV positive, and 6.1% reported that none of their casual partners were HIV positive. Many (30.9%) of the respondents who had had casual sex reported that they did not know the HIV status of their casual partners. Respondents were asked about their condom use during anal or vaginal intercourse with casual partners over the previous six months.

Table 40 – Condom use with casual partner by respondent and partner gender

Number of these that used condoms	Never	Sometimes	Usually	Always
Female respondents				
With regular male partner	2	1	2	4
Male respondents				
With regular male partner	78	160	86	113
With regular female partner	2	0	0	3

As can be seen from Table 40 there are considerable variations in condom use when we examine this by sex of respondent and sex of partner. Again, when we look at these data in terms of the partners' HIV status, a clearer pattern emerges (see Table 41).

Table 41 – Condom use with male casual partner by partners' sero-status

Number of these that used condoms	Never	Sometimes	Usually	Always
Casual partners' HIV Status				
All HIV positive	36	11	3	3
Mixture/unsure	27	118	60	41
All HIV negative	3	2	3	15

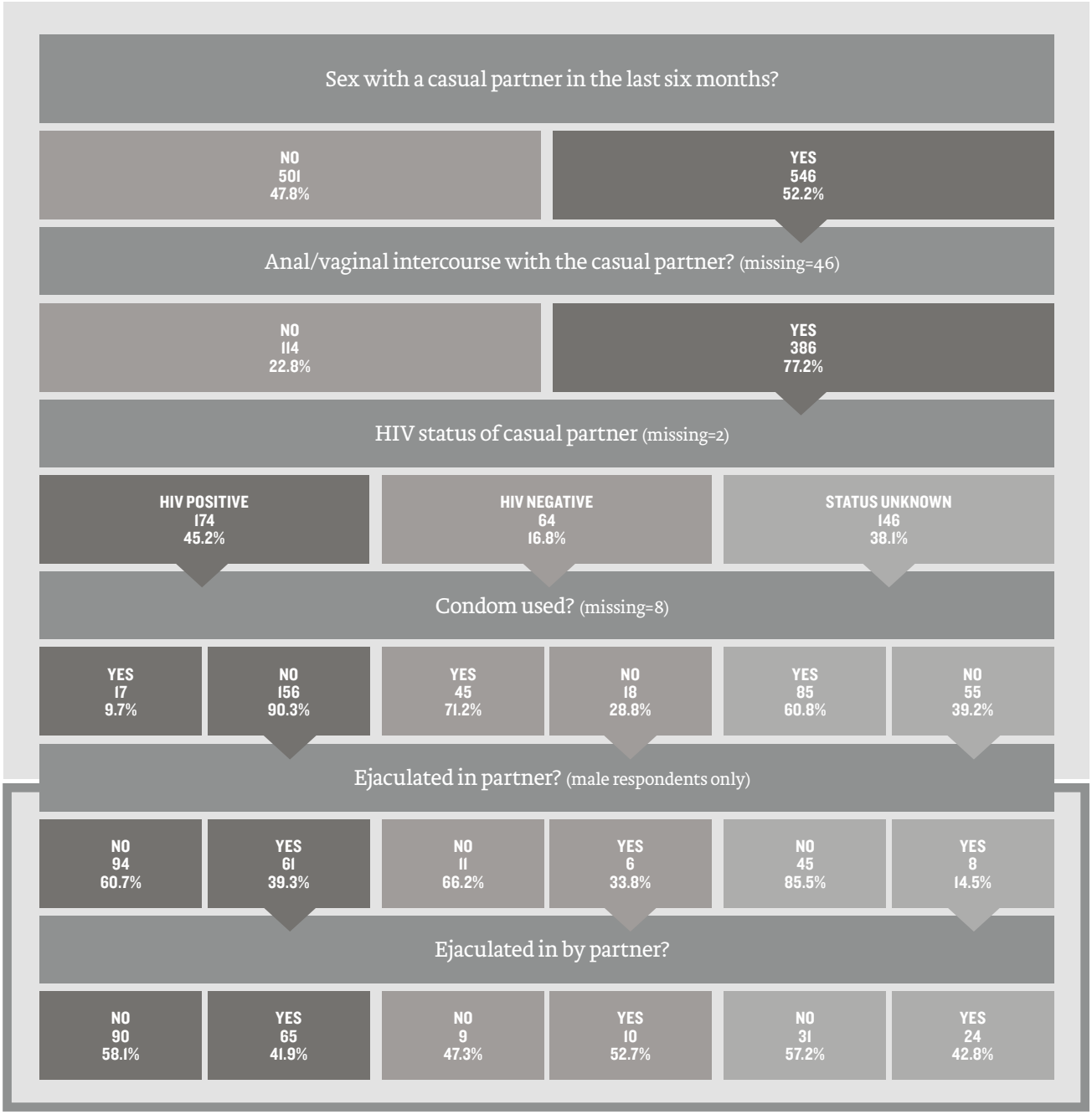
There is a significant relationship between condom use and partners' HIV status: consistent unprotected anal and vaginal intercourse occurs primarily with HIV positive partners, whereas with HIV negative partners or those of unknown status, condom use was much more likely.

In addition to reporting on their overall patterns of condom use, respondents who had had casual sex reported on their most recent sexual encounter with a casual partner. Almost half the survey (47.8%) respondents provided such information. Of the respondents who had casual sex, 77.2% had vaginal or anal intercourse on their last occasion with a casual partner.

As was found for the overall patterns of condom use, condom use during respondents' most recent sexual encounter was contingent on the HIV status of the partner. Figure 7 gives a breakdown of the range of protective strategies employed by positive people to protect their most recent casual partner.

This includes knowledge of HIV status, condom use and avoidance of ejaculation within their partner. This schematic shows that for the entire set of data available, incidents that involved any risk were very rare and mostly associated with partners of unknown status.

Figure 7 – Sexual practice with the most recent casual partner



HIV, sex, relationships and treatments

PLHIV were asked to respond to a number of statements about relationships, sex and HIV. The results of these items are shown in full in Table 42.

When asked whether they would prefer to be in a relationship with someone who is also HIV positive, around half (53.7%) said they would, a third (32.2%) said they would not, and the remainder (14.1%) said that they did not know.

The potential to develop new relationships remains an important issue for PLHIV. While much has been done to reduce stigma and discrimination in formal settings such as workplaces and healthcare settings, the more intimate domains of sex and relationships can still be a site of anxiety and uncertainty for both HIV positive and negative people.

Over two thirds (68.8%) of the respondents agreed with the statement Few people would want a relationship with someone who has HIV. A similar response was found to the statement *I am afraid of telling potential partners of my HIV status in case they reject me.* Over half the respondents (60.0%) agreed with this statement.

Concerns about transmission of the virus to others and re-infection were apparent in the responses to the next six items. Most respondents (66.2%) agreed with the statement *I am afraid of infecting my partner, or potential partner, with HIV, while very few agreed with the statements I feel more confident about unprotected sex because of the new treatments; Withdrawing before ejaculating (cumming) is a way to reduce the risk of passing on HIV*; and *Undetectable viral load means HIV is unlikely to be transmitted to a sexual partner even if I have sex without a condom.* Greater concern on these items was expressed by those with HIV negative regular partners, those having only casual partners and those not currently having sex.

The response to concerns about re-infection remains mixed, with 44.0% agreeing that *I am concerned about becoming infected with another strain of HIV* and 46.2% disagreeing.

When we examine the impact of HIV on sexual pleasure, we find that the majority of the respondents (61.7%) agreed with the statement *HIV has had a negative effect on my sexual pleasure.* One third (33.8%) disagreed with this statement.

When asked about the relationship between partners' HIV status and sexual pleasure here was a greater degree of uncertainty. 18.6% were unsure when asked to respond to the statement *If I know that my partner is HIV positive I find sex more pleasurable.* More respondents agreed with this statement (54.2%) than disagreed with it (29.0%).

Over one quarter (38.2%) said that they agreed with the statement *I have stopped having sex because of my HIV status.* Similarly, 57.6% of participants agreed that *HIV has negatively affected my libido.*

Table 42 – Attitudes to HIV, sex and relationships

Attitudes to HIV, sex and relationships	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
I prefer to have a relationship with someone who also has HIV	9.3	22.9	28.9	24.8	14.1
Few people would want a relationship with someone who has HIV	6.0	19.0	41.3	27.5	6.2
I am afraid of telling potential partners of my HIV status in case they reject me	12.1	19.9	34.3	25.7	8.0
Being HIV positive has helped me form more satisfying relationships	24.3	37.9	17.7	5.9	14.2
I am afraid of infecting my partner, or potential partner, with HIV	9.4	20.5	34.7	31.5	3.8
I feel more confident about unprotected sex because of the new treatments	34.5	35.8	18.7	4.1	7.0
Medical treatments for HIV/AIDS make safe sex less important than it was	39.9	35.4	14.9	4.2	5.6
Withdrawing before ejaculating (cumming) is a way to reduce the risk of passing on HIV	38.3	33.0	19.6	3.3	5.9
Undetectable viral load means HIV is unlikely to be transmitted to a sexual partner even if I have sex without a condom	29.5	34.9	23.4	4.7	7.5
I am concerned about becoming infected with another strain of HIV	16.2	30.0	29.7	14.3	9.7
HIV has had a negative effect on my sexual pleasure	11.9	21.9	32.9	28.8	4.5
If I know that my partner is HIV positive I find sex more pleasurable	10.6	18.4	29.1	25.1	16.8
I stopped having sex because of my HIV status	23.6	35.3	24.0	14.2	2.8
HIV has negatively affected my libido	15.5	22.1	33.2	24.4	4.8

Criminalisation of HIV transmission

Recent high-profile cases of criminal prosecution for HIV transmission in Australia and internationally have changed the landscape within which HIV positive people assess their HIV status and make decisions about how and when to disclose their status. In this year's survey we included questions to assess the impact of these developments on the experiences of PLHIV.

These cases and their ensuing media coverage, as well as an increase in the number of criminal prosecutions for transmitting HIV (Groves and Cameron, 2009), have intensified the discussion about the criminalisation of HIV transmission. A recently published NAPWA monograph explores these issues in depth (see NAPWA, 2009).

Research has shown that dominant views about criminal prosecution of HIV undermines HIV prevention efforts by placing expectation of responsibility solely on the HIV positive sexual partner (Dodds, 2008) and has the potential to reinforce stigma of HIV/AIDS (UNAIDS, 2008).

In 2008, the Department of Health and Ageing produced the National Guidelines for the Management of People with HIV who Place Others at Risk (Dodds, 2008), developed by the Blood Borne Virus and Sexually Transmissible Infections Sub-Committee (BBVSS) of the Australian Population Health Development Principal Committee (APHDPC).

The Guidelines' stated aim is to inform and standardise approaches in the various states and territories to the small number of people for whom coercive measures are needed. It acknowledges that an individual has the responsibility of protecting themselves and others from infection and that in most cases of potential transmission, prevention is best achieved through information, education, and the provision of resources. The Guidelines recommend that the roles of clinician and public health official be kept distinct.

In an AFAO discussion paper, Groves and Cameron (2009) note that the intersection of public health with criminal law is fraught, and the authors highlight the need for discussion about the way in which justice and health agencies can work together effectively.

They recommend further research on the effects on affected communities and point out the need for developing ways to work with journalists to ensure sensitive and accurate reporting of criminal prosecution. They also point to the need to address potential "fallout" issues such as re-establishing trust with doctors.

Table 43 – Attitudes toward legal issues

Attitudes to HIV, sex and relationships	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
I am worried about disclosing my HIV status to sexual partners because of the current legal situation	16.3	27.6	25.6	19.6	10.9
I am worried about disclosing my sexual practice to service providers because of the current legal situation	21.0	36.2	17.3	12.8	12.7

In the survey, we asked participants to what extent the current legal situation has had an impact on their decisions to disclose their status to sexual partners and their sexual practices to service providers.

Clearly legal issues are important to people, with 45.2% agreeing with the statement I am worried about disclosing my HIV status to sexual partners because of the current legal situation.

There was less concern about the legal implications of disclosure of sexual practices to service providers, however 30.1% expressed some concern and 12.7% were uncertain.

CHILDREN

18.7% of those surveyed currently have children and 6.4% have dependent children. We were also interested in future plans for children among PLHIV. Most PLHIV (73.4%) were not currently considering having children.

Of the remainder, 21 PLHIV had decided to have children in the future and 1 is attempting to have children. 42 were considering having a child, but have not decided, and 21 people have considered having a child, but have decided it is too risky. Three respondents were pregnant. While a greater proportion of women (heterosexual, bisexual and lesbian) were considering, or had considered having children, some of those doing so are gay, bisexual or heterosexual men.

Table 44 – Planning to have children (number)

	Gay or Bisexual Men	Hetero -sexual Men	Women	Total
No	673	23	29	773
No, I already have children	47	14	38	105
I have decided to have a child/children in the future	13	2	4	21
I am currently trying to conceive/ get pregnant	-	1	3	1
I am currently pregnant	-	-	8	3
I have thought about it but I haven't decided	31	-	2	42
I have thought about it but I have decided that it is too risky	17	1	1	21
I don't have enough information to make a decision	2	-	-	4
Other	28	3	5	29

RECREATIONAL DRUG USE

Practices

Respondents were asked about their use of a range of non-prescription drugs, both those legally available and those that are currently prohibited in Australia.

Respondents were asked which of a list of substances they had used in the last twelve months. For those drugs which are commonly injected, differentiation was made between injection and other means of administration.

Table 45 gives these results. As can be seen from these data, alcohol was the most commonly used drug followed by tobacco. Other drugs that are popular in the gay and dance party scenes (amyl, ecstasy, non-injected speed and LSD) were also used by PLHIV.

In addition we asked people the amount of alcohol they consumed: of those who drank, 47.4% drank less than once per week, 28.5% drank weekly and 24.0% drank daily. Similarly, with marijuana, 36.8% smoked less than once a week, 14.7% weekly and 28.4% daily.

It must be noted that we only asked respondents if they had used each of the other drugs in the previous twelve months, not how often they use them. Use of many drugs is occasional rather than regular and this may inflate the rates reported here. Gay male respondents were significantly more likely than other groups to have used alcohol, ecstasy, amyl and crystal-meth and less likely to have used heroin (injected) and prescribed methadone.

Table 45 – Recreational use of drugs (percentage of sample)

Drugs	Percent
Alcohol	79.5
Tobacco	30.2
Marijuana	35.9
Amyl	34.1
Ecstasy	13.6
Viagra or similar	27.7
Crystal Meth	16.5
Speed (not injected)	5.5
Speed (injected)	4.5
Cocaine (not injected)	7.1
GHB/GBH/Fantasy	7.1
LSD/trips	3.4
Steroids (injected)	1.6
Heroin (injected)	1.9
Methadone (prescribed)	1.4
Other	3.3

(Multiple responses possible)

Home, work and money

ACCOMMODATION

We asked a series of questions about participants' accommodation status and experiences. These experiences vary considerably among PLHIV, most particularly as a function of whether individuals are in private or public accommodation.

Current accommodation

The current type of accommodation of the respondents can be seen in Table 46. Similar numbers of PLHIV were in accommodation that they own or rent through the private system. A smaller number of people were in public rental accommodation. These were more likely to be those on a government benefit.

Table 46 – Current accommodation of respondents (percentage of total sample)

Accommodation	Percent
Own or purchasing house or flat	41.5
Private rental accommodation	34.1
Public rental accommodation(government owned)	12.8
Rent-free (e.g. provided by friends, family, etc.)	4.8
Community housing/housing co-operative	3.8
Other	3.1

Households varied considerably. 41.2% of PLHIV lived by themselves, while the remainder lived with between 1 and 8 other adults (median=1) and with between 1 and 4 children (for those living with children: mode=1 median=1). Around one third (31.9%) lived with a partner or spouse, and 5.7% lived with dependent children. In addition, 6.6% lived with other family members and 17.0% with a flatmate.

49.2% of PLHIV also lived with pets. The most common pets were dogs and cats. Other companion animals included fish, birds, rabbits and farm animals. 76.1% of respondents had access to a car. When asked how easy it was to access public transportation, 12.5% said it was very difficult, 13.3%, difficult, 36.1%, easy and 38.0%, very easy.

EMPLOYMENT

The area of employment continues to present challenges to HIV positive people.

While the need for financial security, social contact and a sense of worth are critical factors in HIV positive people's wishes to be in paid employment, the management of HIV disclosure, the intermittent effects of illness and the need for flexibility around taking time off can prove substantial barriers to obtaining and retaining employment.

There are also considerable obstacles for those who have left employment in the past and are attempting to return to the workforce. These include de-skilling, explaining an extended absence for the workforce, issues of aging and changes in life goals.

Employment status

Just over half (58.2%) of the respondents were currently employed, with more being in full-time work (38.5%) than those in part-time work (19.7%). The remainder tended to describe themselves as either not working/home duties/retired (19.7%) or unemployed (10.6%). 11.9% said their work was HIV-related.

Of those who were working, the mean number of hours worked was 37.8 per week (median=38.0). Those working full time worked an average of 43.5 hours per week (median=40.0) and those in part time employment worked an average of 22.6 hours/week (median=22.2).

Table 47 – Employment status

Employment	Percent
Work full-time	38.5
Not working/Retired /Home duties	19.7
Work part-time	14.7
Unemployed	10.6
Student	4.6
Other	11.8

Impact of HIV on employment

We asked respondents how their initial HIV diagnosis affected their career plans. These data are shown in Table 48 below. A large proportion indicated that their career ended at their time of diagnosis (16.4%).

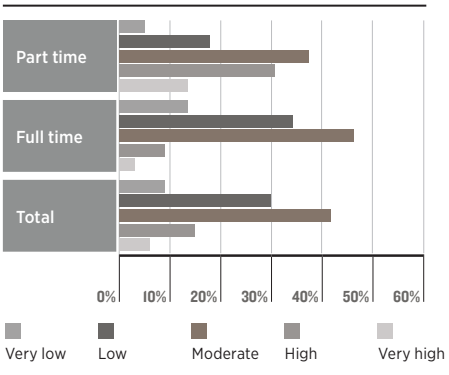
Table 48 – Impact of HIV diagnosis on career plans (percentage of sample)

Impact	Percent
My career plans did not change	31.6
It was more difficult to plan for the future	24.3
My career ended/I stopped work	16.4
A career was no longer as important	13.7
I changed careers	9.9
I was less likely to change careers	4.0

Those currently in paid employment

Respondents were asked about the level of stress in their current job. Two fifths rated the stress level as moderate (40.7%) while 29.4% said it was high and 9.0% said it was very high. Only 5.7% rated the stress level as very low and 15.2% said there was low stress (see Figure 8). Those in full-time work were somewhat more likely to report stress.

Figure 8 – Stress at work



Confidentiality in the workplace remains a critical and complex issue for positive people, particularly given ongoing experiences of discrimination. When asked what difficulties they experience around confidentiality at work, 16.1% said that they did not attempt to keep their status confidential (see Table 49).

63.6% said they have experienced no problem in this area. Of those who did experience difficulties, the greatest problem appeared to be gossip, followed by issues around explaining absences from work, and medication.

When we examine the difficulties associated with confidentiality in terms of whether the respondent works in an HIV related job, we find that those in HIV related employment were less likely to wish to keep their status confidential and had fewer problems when they do chose to do so.

Table 49 – Difficulties with HIV status confidentiality in the workplace: percentages of total and specific samples

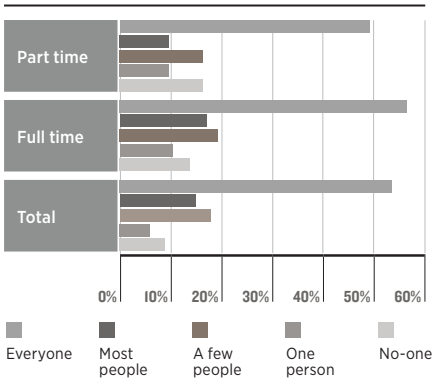
Difficulties	Total working sample	AIDS related	Non-AIDS related
No problems	63.6	36.9	70.2
I do not try to keep my HIV status confidential	16.1	57.8	10.4
Gossip	7.2	4.1	8.0
Explaining absences from work	11.2	2.8	12.9
Visible signs of illness	7.7	4.7	8.5
Difficulty keeping and taking medication	3.4	1.9	3.8
Other	3.3	1.5	3.7

(Multiple responses possible)

When asked how many people in their workplace knew that they were HIV positive, 9.7% said that everyone knew, 7.8% said most people knew, 17.6% said a few people knew, 14.6% said one person knew and 54.6% said no-one knew (see Figure 9).

Those working in a HIV related job were more likely to say everyone knew their HIV status than those in non- HIV related work (42.1% versus 2.5%) and similarly less likely to say no-one knew their HIV status (12.4% versus 61.0%).

Figure 9 – Disclosure in workplace



When asked about the impact that HIV had on their capacity to perform their work duties, over half of the sample said that their work was unaffected (see Table 50). One third said that they tired more quickly, and one fifth said that they had difficulty concentrating.

Table 50 – Impact of HIV on work capacity (percentage of those in paid employment)

Impact	Percent
It is not affected	53.9
I tire more quickly	35.2
I have difficulty concentrating	16.6
I am less productive	11.2
I cannot always go to work	10.3
I work reduced hours	9.7
I do different duties	2.0
Other	3.9

(Multiple responses possible)

Living with HIV often involves intermittent periods of ill health, particularly around treatment changes and the need to access health and other services, often only available during work hours (Prestage et al. 2001). Respondents were asked how much flexibility their workplace gives them to take time off for reasons relating to HIV.

Most PLHIV had the capacity to take time off for medical appointments (see Table 51 below) and illness. There was less capacity to take time off for counselling and few had much capacity to take time off to engage in volunteer work.

Table 51 – Capacity within workplace for HIV related interruptions (percentage of those in paid employment)

Capacity	Never	Seldom	Sometimes	Often	Always
For medical appointments	7.3	4.2	17.2	15.0	56.3
For counselling	22.0	9.1	19.0	9.7	40.1
When you are sick	3.7	3.6	15.0	13.3	64.4
To do volunteer work	43.7	10.1	16.6	4.8	24.9

FINANCES

The HIV Futures surveys have highlighted the financial difficulties that many PLHIV contend with. These difficulties cannot be explained simply by the proportion of PLHIV relying on government pensions or benefits. There are financial hardships associated with being HIV positive. Some of these are structural and systemic, for example the costs associated with managing the negative consequences of treatment, some result from stigma and disadvantage that result from reduced employment options, while others are the cumulative effects of living for many years with uncertain or fluctuating health and well being.

Income

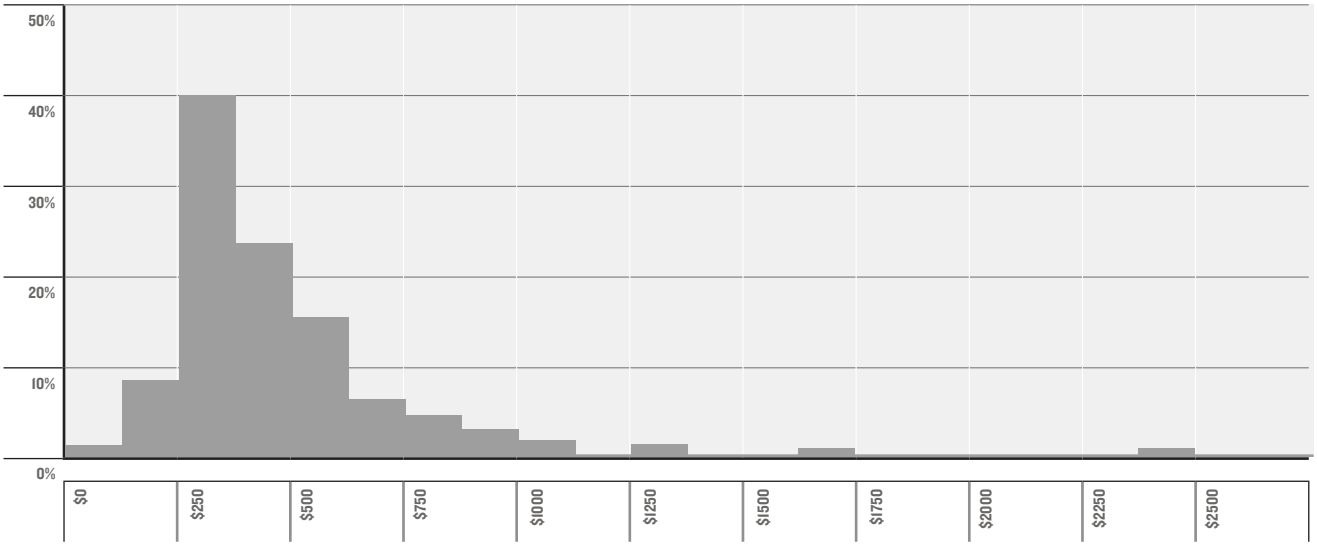
The source of income of the survey respondents is shown in Table 52 below. As with the previous HIV Futures survey, there were more people receiving a salary (47.1%) than on a government benefit (38.1%), suggesting an encouraging trend.

Table 52 – Primary source of income: percentage of total sample

Income	Percent
Salary	47.1
Benefits/pension/social security	38.1
Superannuation/annuity/savings	5.7
Other	5.7
Partner supports me	2.9
Family/friends support me	0.6

The median weekly in-hand income for respondents was $541 and $662 excluding those reporting zero income. Figure 10 below gives the distribution of income in $125 intervals. The peak of the distribution corresponds to the income that one is likely to receive on a government pension. 23.5% of respondents had a partner with whom they share financial resources. The partners' median weekly income was $800.

Figure 10 – Histogram of respondents'weekly income after tax



Expenditure and debts

Respondents were asked their weekly expenditure on a range of items. The results are shown in Table 53 below. The total mean expenditure on medication was $74 per week. Mean rental or mortgage costs were $323. Food and utilities accounted for around $130 and $77 respectively. 21.7% of respondents owned their own home, while 22.2% were paying off their home. 25.0% received a rental subsidy averaging at $168.9per week (median= $70). Respondents were also asked their current debt burden as one measure of the financial impact of HIV. This averaged at $33,000 with a median of $100.

Table 53 – Weekly expenditure on medications and essentials ($AU)

Expenditure	Mean	Median
Rent or mortgage repayments	$323	$250
Food	$130	$100
Utilities	$77	$60
Complementary therapies	$35	$20
Other medication	$22	$11
Antiretroviral drugs	$17	$10

Assessments of benefits

People receiving a pension may undergo an assessment by a Commonwealth Medical Officer. As there has been considerable community discussion about the impact of these assessments we asked respondents about their experiences. A total of 26.6% (n=231) of those receiving a benefit in the previous two years had received such an assessment.

When asked what this experience resulted in, only 6.9% (n=16) said that their benefit was terminated (See Table 54 next page). 23.4% said that the assessment resulted in changes to their conditions of benefit. Importantly the experience of assessment resulted in distress for two fifths of the respondents while it clarified concerns for around one in ten.

Table 54 – Consequences of receiving an assessment of benefit from a Commonwealth Medical Officer (percentage of those assessed in last 2 years)

Consequences	Percent
Require documentation from your doctor	56.2
Cause you distress	58.9
Result in changes to the conditions of your benefits	23.4
Result in an independent assessment	16.1
Clarify concerns that you had	11.6
Result in a shift from Pension to Newstart allowance	6.8
Result in termination of your benefits	6.9

(Multiple responses possible)

POVERTY

As with the previous HIV Futures surveys, we have used the quarterly Henderson Poverty Lines published by the Melbourne Institute of Applied Economics and Social Research to assess the extent of poverty among PLHIV. The Henderson Poverty lines are set for specific income units. These units include the individual, any partner with whom they share financial resources and any dependent children. We used the Institute's data for the December 2011 quarter (Melbourne Institute of Applied Economic and Social Research, 2012), the time at which the survey was completed.

According to this measure over one quarter (28.6%) of PLHIV were living below the poverty line. That this figure has remained so high across the ten years of the HIV Futures surveys suggests that current resources and strategies are inadequate and decisive action must be taken to address this pocket of severe social disadvantage.

Correlates of poverty

We look now at the differences between different groups in their likelihood to be living in poverty. Those in paid employment were significantly less likely to be classified as below the poverty line.

Two fifths of those not in paid employment were living in poverty (see Table 55).

Table 55 – Poverty by employment status (percentage of employment categories)

Employment status	Below poverty line	Above poverty line
Employed	11.7	88.3
Not employed	44.4	55.6

$\chi^2_{(1,1)} = 138.190$, $p<0.001$

Respondents who identified a salary as their primary source of income were significantly less likely to report an income below the poverty line. Over half of those on a government benefit were living in poverty (see Table 56).

There was no gender difference in the proportions of people living below the poverty line.

Table 56 – Poverty by income source

Income type	Below poverty line	Above poverty line
Salary	8.9	91.1
Super/annuity/savings	22.4	77.6
Partner/ Family/friends/ Other	33.0	67.0
Benefits/pension/social security	48.7	51.3

$\chi^2_{(3,1)} = 175.372$, $p<0.001$

There is also a clear relationship between poverty and self-rated health and well being (see Table 57 and Table 58). Those living below the poverty line were significantly more likely to rate these characteristics as poor or fair.

This pattern most likely represents an interaction between poverty and these factors, rather than a directional relationship. Worse health and well being limit access to employment and financial security, while poverty creates emotional distress, limits social interaction and damages health.

Table 57 – Self-rated health of those above and below the poverty line (percent within poverty group)

Self-rated health	Below poverty line	Above poverty line
Poor	47.2	52.8
Fair	36.0	64.0
Good	25.9	74.1
Excellent	20.2	79.8

$\chi^2_{(3,1)} = 29.531$, $p<0.001$

Table 58 – Self-rated well being of those above and below the poverty line (percent within poverty group)

Self-rated health	Below poverty line	Above poverty line
Poor	46.6	53.4
Fair	36.5	63.5
Good	24.4	75.6
Excellent	15.4	84.6

$\chi^2_{(3,1)} = 47.440$, $p<0.001$

Costs

As with previous surveys, we asked respondents about the difficulty they had paying for a range of activities, goods and services. The results are shown in Table 59 below, with the not applicable responses excluded from the calculation for each item.

The items that most respondents rated as very difficult to pay for were quality of life costs like travel, going out, recreational drugs and entertainment. Those items most likely to be rated as not at all difficult were support services, medical services and medication. Importantly substantial proportions rated food, clothing, utilities and rent as very difficult. The experience of difficulty in meeting the costs of these items was rarely restricted to one area. That is, when individuals had difficulty paying for food, they also experienced difficulties with rent, utilities and quality of life items.

When we examine the ratings of these items for those above and below the poverty line, those living in poverty were more likely to rate all items as very difficult (see Table 60 on next page).

Disturbingly, among those living below the poverty line, one quarter rated paying for medical services as very difficult, while the proportions that gave this response for co-payments for medication and costs of other prescribed medication are also very concerning.

When it comes to the basics of life, substantial numbers of those below the poverty line also rated these as very difficult.

Table 59 – Difficulty paying costs of items and services

Difficulty paying costs	Not at all difficult	A little difficult	Very difficult
Co-payments for medication for HIV/AIDS (n=724)[3]	63.7	26.8	9.5
Other prescribed medication (n=872)	56.2	34.1	9.7
Medical services (doctor, dentist, etc.) (n=891)	56.1	28.4	15.5
Complementary Therapies (n=614)	52.4	26.9	20.7
Support services (counselling, etc.) (n=491)	67.5	17.6	14.9
Entertainment (theatre, movies, concerts, etc.) (n=875)	38.3	29.0	32.7
Going out (eating/drinking) (n=911)	33.9	33.0	33.1
Sport (exerrcise, gym, etc.) (n=688)	44.8	29.0	26.2
Recreational drugs (n=377)	40.1	26.6	33.2
Travel/holidays (n=844)	27	26.6	46.4
Rent/Mortgage/Housing costs (n=873)	40.6	39.0	20.3
Utilities (telephone/electricity/gas/water) (n=971)	39.6	36.7	23.7
Food (n=980)	47.9	35.0	17.1
Clothing (n=948)	40.2	30.4	29.4
Transport (n=924)	47.7	33.5	18.8
Child care (n=77)	69.8	7.2	23

3 Ns refer to the number of participants that identified this as an applicable cost. That is, those selecting 'not applicable' or giving no response are excluded from the percentages reported in that row.

Table 60 Difficulty paying costs of items and services by poverty status

Difficulty paying costs	Below poverty line			Above poverty line		
	Not at all difficult	A little difficult	Very difficult	Not at all difficult	A little difficult	Very difficult
Co-payments for medication for HIV/AIDS (n=193, 531)[4]	53.4	32.4	14.2	67.5	24.7	7.8
Other prescribed medication (n=230, 641)	42.0	43.2	14.9	61.3	30.8	7.9
Medical services (doctor, dentist, etc.) (n=227, 664)	46.3	26.3	27.4	59.4	29.2	11.4
Complementary Therapies (n=150, 464)	33.6	29.6	36.7	58.4	26.0	15.6
Support services (counselling, etc.) (n=127, 364)	59.7	20.8	19.5	70.3	16.5	13.3
Entertainment (theatre, movies, concerts, etc.) (n=227, 648)	18.7	27.7	53.6	45.2	29.5	25.3
Going out (eating/drinking) (n=230, 681)	14.0	28.7	57.2	40.6	34.5	24.9
Sport (exercise, gym, etc.) (n=170, 518)	22.8	31.5	45.7	52.1	28.1	19.8
Recreational drugs (n=107, 269)	22.5	21.5	56.0	47.1	28.7	24.2
Travel/holidays (n=211, 633)	10.7	21.1	68.1	32.4	28.5	39.1
Rent/Mortgage/Housing costs (n=219, 654)	27	44.5	28.5	45.2	37.2	17.6
Utilities (telephone/electricity/gas/water) (n=254, 717)	22.7	40.1	37.2	45.6	35.5	18.9
Food (n=262, 718)	27.5	46.5	26.0	55.3	30.8	13.9
Clothing (n=248, 701)	22.2	36.1	41.7	46.6	28.3	25.1
Transport (n=239, 686)	27.4	40.9	31.7	54.8	30.9	14.3
Child care (n=14, 63)	69.3	8.9	21.8	69.9	6.9	23.3

DISCRIMINATION

Discrimination on the basis of HIV is unlawful in all jurisdictions in Australia. The introduction of anti-discrimination legislation has offered an avenue of redress for those with the energy and courage to pursue it, acts as a deterrent for employers, service providers and the like, and sends a clear message that such discrimination is unacceptable to the Australian population.

However, PLHIV continue to experience less favourable treatment in many domains of their lives. While more detailed research is needed to adequately assess the specific impact of this treatment, we can reasonably imagine that the impact goes beyond the direct outcomes of the actions and is detrimental to both health and quality of life.

In addition the anticipation of discrimination may limit people's life choices in subtle but sustained ways. We have asked about the experience of discrimination in a range of settings.

Accommodation

7.4% of respondents indicated that they had experienced less favourable treatment in relation to accommodation (2.8% in the last two years).

4 Ns refer to the number of participants below and above the poverty line respectively that identified this as an applicable cost. That is, those selecting 'not applicable' or giving no response are excluded from the percentages reported in that row.

Health services

27.6% of respondents had experienced less-favourable treatment at a medical service as a result of having HIV. This comprised 13.0% of all respondents that had experienced such discrimination in the last two years and 14.6% that experienced this more than 2 years ago.

When asked what form this discrimination took, the most common responses were avoidance (43.5%) confidentiality problems (38.7%) and increased infection control (39.1%). These experiences are shown in Table 61.

Table 61 – Form of HIV-related discrimination experienced at medical service (percentage of those experiencing discrimination)

HIV-related discrimination	Ever (N=284)	In last 2 years (N=133)
Avoidance	43.5	42.8
Confidentiality problems	38.7	41.7
Increased infection control	39.1	31.4
Refusal of treatment	23.9	21.0
Treated last	33.8	30.2
Rushed through	29.2	32.2
Harassment	15.6	17.4
Abuse	10.6	10.0

(Multiple responses possible)

Insurance

38.7 % of respondents currently had private health insurance and 15.6 % currently had some other form of income or mortgage insurance.

23.4 % of respondents indicated that they had experienced less favourable treatment in relation to insurance. The most commonly reported example of less favourable treatment was being unable to take out an insurance policy, for example health insurance and travel insurance.

Workplace

15.4% of respondents had experienced less-favourable treatment in the workplace as a result of having HIV. This comprised 4.8% of all respondents that had experienced such discrimination in the last two years and 10.6% that experienced this more than 2 years ago. When asked what form this discrimination took the comments ranged from unfair dismissal to reduced advancement opportunities to bullying.

Appendix

METHODS AND INSTRUMENT

This section describes the research design, method of recruitment, development of the survey instrument, sampling issues and data analysis.

The survey instrument

HIV Futures is an anonymous, cross-sectional survey of a sample of people living with HV/AIDS in Australia. The HIV Futures 7 survey ran from October 2011 through April 2012. The survey was available as both a self-complete mail back survey and on-line. This is the second time that HIV Futures has been made available on-line, reflecting the growing use of the internet amongst Australian households.

On-line surveys have been used successfully to collect health information from GLBTI Australians and same sex attracted young people in Australia (Hillier et al., 2005, Pitts et al., 2006). We hoped that by offering HIV Futures online we would provide an easier way for the usual demographic of respondents to complete the survey and also allow us to access harder to reach PLHIV, such as those living in rural or regional areas, or those not in contact with HIV/AIDS services. The on-line survey was accessed through the website www.HIVfutures.org.au. The site was hosted by Demographix.co.uk, an experienced commercial provider of web-based surveys with excellent attention to issues of security and privacy.

Design

The instrument was based in large part on the HIV Futures 6 survey (Grierson et al., 2009), which in turn was adapted from the five previous surveys (Ezzy et al., 1998, Grierson et al., 2000, Grierson et al., 2004a, Grierson 2006). The survey content was developed in consultation with a number of organisations and individuals from the HIV/AIDS sector (see Consultations section below). Most items were retained in their original format to allow comparisons between the six studies.

New questions and options were added to reflect changes in the context in which people live with HIV/AIDS in Australia, including policy and service changes over the past three years. Questions were also edited, and some removed, to make the survey easier to complete.

The survey consisted of 170 items organised into eight sections: demographics; accommodation; health and treatments; services and communities; sex and relationships; employment; recreational drug use; and finances. Each section included an explanation of the purpose of the items. Most items in the survey were closed-coded with either single or multiple response options.

'Other' categories were included for most items to ensure that significant experiences of living with HIV were not excluded. There was a number of attitude/ belief items scored using a four- and five-point Likert scales. There were also write-in and open-ended items.

The online survey used identical wording to the paper survey and contained exactly the same items, however the online survey provided users with pull-down menus for some items, such as numbers, years and months. These were included in order to ensure relatively clean data. The online survey also had a number of skips built into it so that respondents did not have to see items that were not relevant to them, for example, respondents who were not taking antiretroviral treatments did not have to see the questions about these treatments.

Completed paper surveys were returned in a reply-paid envelope to La Trobe University. Respondents were also able to add their contact details to the program mailing list to receive reports and to participate in further research by completing an additional form and sending it in a separate envelope.

On-line surveys were able to be saved and re-opened by respondents so that they could be completed in their own time. Completed surveys were submitted online and stored by demographix.co.uk. Respondents completing the survey online were also able to provide researchers with their contact details by filling in and submitting a separate form, which was stored in a database separate from the survey data.

RECRUITMENT AND SAMPLING

There is no register of HIV positive Australians, as HIV testing is voluntary and anonymous. As the survey was anonymous and as multiple recruitment strategies were employed a simple response rate cannot be calculated. Recruitment took place using a set of methods in order to reach a diverse population of HIV positive Australians.

This approach meant that some participants received multiple copies of the survey from different sources. Recruitment was also combined with a promotion strategy that increased community awareness of the research and its utility. The inside front cover of the paper survey also contained the link to the online survey so that each participant receiving a paper copy was also informed about the availability of the on-line survey.

1. Direct distribution

One copy of the survey was mailed directly to individuals who participated in HIV Futures 5 and expressed interest in participating in future research conducted by the Living with HIV program at ARCSHS. Potential participants were able to request a copy of the survey by telephoning the free call number, emailing the researchers.

2. Promotion and marketing

Paid Advertising

The survey was advertised in a number of gay newspapers with distribution around the country. Banner ads with a direct link to the on-line survey were placed on: **gaydar.com.au**.

Advertising through community organisations

The survey was promoted extensively through community organisations. Advertisements, articles and news items were placed in community newsletters, banner ads were placed on community websites and promotional postcards and reception cards were placed at reception desks.

3. Community sites

In addition to advertising the survey, community organisations were involved in promoting the study by mailing the survey to members accompanied by a covering letter from the organisation explaining the purpose of the study, explaining the value of the research, and encouraging participation.

The survey forms were made available on-site at numerous community organisations around the country. These organisations also distributed copies of the survey to sites and venues they felt were appropriate and with whom they have ongoing relationships. Staff at some organisations also assisted people to complete surveys. The survey was also promoted at staff and volunteer meetings.

4. Clinical sites

a. General Practitioners

Copies of the survey, postcards and reception cards were mailed directly to clinical practices that see a significant number of HIV positive clients. This included, but was not limited to, the S100 prescribers. The survey the web link was also promoted by ASHM (Australasian Society for HIV Medicine) to its members and email lists.

b. Hospital settings

Where ethical approval was obtained, the survey was available in the waiting areas of a number of HIV and Infectious Disease clinics or distributed directly to clients by staff. Surveys were also available through social workers in some hospitals.

c. Other clinical sites

Surveys were also distributed through sexual health centres and community health centres including those with a specific HIV focus. Generally these were available in waiting rooms, although some distributed them directly to clients..

JUSTIFICATION OF STUDY METHODOLOGY

HIV Futures is a cross-sectional study of a sample of HIV positive Australian residents. A cross-sectional study is one in which a new sample is collected on each occasion. While a proportion of the sample may have completed the previous surveys, the responses for each survey are not formally linked, so that direct comparison between individuals' responses over time is not possible. The cross-sectional methodology was chosen for the following reasons.

The HIV Futures surveys are anonymous. HIV/AIDS remains a sensitive issue for many PLHIV in Australia. Our previous research and that of our colleagues tell us that PLHIV still experience stigma and discrimination.

Allowing the survey to be completed anonymously helps to allay PLHIV's concerns that information about their HIV status and the other issues addressed in the survey may be compromised.

Secondly, the survey is national. It would not be possible to achieve this with a cohort design, since the relative ratios of states and territories require adjustment for each survey. The distribution of the survey also relies on diffusion through community groups in a manner that maintains the anonymity of respondents, particularly those in regional areas.

Thirdly the survey is self-complete. This means that PLHIV can complete the survey in a setting that is comfortable and safe for them and in their own time. Feedback from participants during this study indicated that some people completed the survey over a number of days or weeks, and that individuals consulted their medical practitioners and other records to verify some of the details included in the survey.

Fourth, the population of HIV positive Australians is constantly evolving. A cross-sectional survey allows us to include newly HIV positive individuals as well as those who have been positive for some time. These groups may have an overall similar experience of living with HIV, but the differences between them can be profound.

There are also certain limitations associated with the recruitment method used.

Caution must therefore be exercised in the application of the findings of this research to individuals who are less likely to be included in the sample, such as people with limited literacy, people of non-English speaking background, and those who are particularly geographically or socially isolated. We have taken a range of measures to address these issues.

For example, participants were offered the option of completing the survey over the telephone either directly with the researchers using a free call number, or with service providers. In addition, the Telephone Interpreter Service (TIS) was promoted as a way of completing the survey for non-English speakers, either by telephone or in person.

Surveys were also completed with the assistance of service providers or community agency workers for those with literacy problems or those with physical impairment. The combination of clinical and community setting for study recruitment was intended to optimise access to the study. This means that people are not disadvantaged from entering the study if they are not currently using anti-retroviral therapies or not currently in contact with one of the main HIV treatment providers.

Nevertheless it must be acknowledged that this methodology will never be appropriate for some members of the PLHIV community. This is particularly so for those from culturally and linguistically diverse backgrounds who may be marginalised even within their own communities, and those for whom invisibility is the key to their continuing safety.

Community development methodologies are currently being explored in order to establish how the very real needs of these people can be understood and documented over time within an action research framework which offers support and strengthens networks as the research proceeds.

It cannot be stressed strongly enough that no piece of research should be used in isolation. Each study gives a different perspective on the HIV epidemic, and collectively they lead to a greater understanding of the dynamics of the epidemic and the issues affecting Australian PLHIV.

CONSULTATIONS

Consultation around the HIV Futures Study was undertaken in three ways:

1. We engage directly with representatives of our three partner organisations: The National Association of People With HIV Australia (NAPWHA), The Australian Federation of AIDS Organisations (AFAO) and The Australasian Society for HIV Medicine (ASHM). These organisations co-ordinate the involvement of their member organisations around the country and provide consolidated advice and guidance for this project
2. Consultations were conducted with State and national bodies in person and by mail prior to the finalisation of the research instrument. This included feedback on the survey content and on recruitment strategies.
3. Consultation was also undertaken with key individuals around the country including clinicians, treatments officers, mental health workers and service providers. Particular consultation was undertaken with hepatitis C organisations and clinicians to ensure that the expanded hepatitis C section of the survey was appropriate and useful.

WEIGHTING

In order to ensure that the results reported in this document accurately represent the Australian population of PLHIV, comparisons were made to the Australian HIV Surveillance Report (Kirby Institute 2012) and the data were weighted to conform to the demographic profile of the Surveillance Report. A weighting algorithm based on mode of infection, gender, state of residence and diagnosis of AIDS defining illness has been applied to all the analyses that follow. Consequently, findings are presented in terms of sample percentages rather than frequencies. Sample sizes (Ns) are given when the table represents a subset of the total sample. These Ns are weighted.

ANALYSIS

Statistical comparisons including ANOVA and chi-square have been employed in the analysis of the data, although for clarity the details of these are not included in this report. All significant differences reported have a probability of at most $\alpha = 0.01$.

FURTHER ANALYSIS AND REPORTS

As with the previous HIV Futures surveys, a number of reports and specific issues papers analysing specific populations and specific issues will be produced over the coming years.

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CONTACT

Australian Research Centre
in Sex Health and Society

General enquiries
T +61 3 9479 8700
F +61 3 9478 8711
E arcshs@latrobe.edu.au